THE COMPLEX PATIENT’S EXPERIENCE WITH DEPRESSION:
THE ROLE OF COMPETING ILLNESS IN DEPRESSION
SYMPTOM IMPROVEMENT

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ABSTRACT

Background: Growing evidence shows the co-existence of physical chronic illnesses and mental health disorders like depression can confound and hinder physical symptom improvement and depression treatment.

Objectives: The purpose of this mixed methods study was examine the potential relationship between coexisting illness severity and change in depression over time; and to identify contextual factors that influence beliefs, attitudes, and treatment preferences for depression and coexisting illness care for primary care patients experiencing a new episode of depression.

Participants and Setting: 168 primary care patients experiencing a new episode of depression recruited from a primary care network in Denver, Colorado. Nineteen participants were interviewed for the qualitative portion of the study.

Measures: Patient Health Questionnaire-9 (PHQ-9) to measure depression, and the Cumulative Illness Rating Scale (CIRS) to measure illness severity.

Results: Hierarchical Linear Modeling analyses revealed CIRS was not a statistically significant predictor of change in depression over time give the estimated variance components for the PHQ-9 reliabilities were low (Intercept = 0.42; Time Slope = 0.054).

Participants described a variety of causes for their depression including coexisting illnesses as well as describing coexisting illness as a competing demand to seeking mental health care. Additionally, in spite of a new diagnosis of depression, participants for the most part continued to focus on physical ailments and controlling existing chronic disease.
Conclusions: Although this study did not show a statistical relationship between chronic illness severity and change in depression, qualitative findings did suggest that illness severity has some influence on depression symptoms which should be further tested. The interviews offer some challenges to the potential assumptions of depression interventions in primary care settings that may see depression as a separate condition from patients’ chronic illnesses and need isolated treatment. It can be theorized that the patients interviewed for this study see their depression as the result of many of the difficulties associated with illness complexity. Though this study was unable to identify a relationship between chronic illness severity and depression symptom improvement, additional efforts are needed to improve the understanding of chronic illness burden on depression outcomes.

The form and content of this abstract are approved. I recommend its publication.

Approved: Debbi Main
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Mentors along the way: Basil Walter, Max Contreras, Jon Stewart, Robert F. Kennedy, and Ernesto Galarza.
DEDICATION

To my mother, Blanca Velasco, who I know is proud of her son and even more proud that I have spent so much time studying a disease that needs attention and care. I love you very much and I hope to continue to make you proud.

I would not be who I am today without the love from my grandmother Lucy Caballero.

To my grandfather, Catarino Moralez Jr., who didn’t make it to see me finish but called me “doctor” anyway…

To Debbi Main, for rescuing me when I had no idea what I was doing, or where I was going. You took me on and made sure I found something I was passionate about and that I was developing the fortitude to finish. Thank you Debbi, I truly would not have done this without you.
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CHAPTER I

INTRODUCTION

The Centers for Disease Control and Prevention (CDC) estimate that by 2020, depression will be the second leading cause of disease burden in the U.S. behind cardiovascular disease (Centers for Disease Control and Prevention, 2013). Depression is a debilitating illness typically associated with a loss of pleasure in activities and perceptible changes in mood and behavior such as sleeping patterns, appetite, and concentration, as well as feelings of hopelessness (Gilbody, 2011; National Institute for Health and Clinical Excellence (NIHCE), 2009). Both the CDC (2010) and the NIHCE (2009) confirm that depression is more prevalent among people with chronic illnesses and the coexistence of chronic physical health problems can cause and complicate depression. The NICHE report concludes that “depression is approximately two to three times more common in patients with a chronic physical health problem then in people who have good physical health” (2009).

Growing evidence shows the co-existence of physical chronic illnesses and mental health disorders like depression can confound and hinder physical symptom improvement and depression treatment (Gonzales, Esbitt, Schneider, Osborne, & Kupperman, 2011; Katon & Schulberg, 1992; Koike, Unutzer, & Wells, 2002; Nutting, Rost, Smith, Werner, & Elliot, 2000; Pagoto, Schneider, Appelhans, Curtin, & Hajduk, 2011; Rost, et al., 2000; Rutledge, Reis, Linke, Greenberg, & Mills, 2006). Depression has a bi-directional relationship with physical illness in that it adversely affects the severity of physical illness, but similarly the presence of physical illness exacerbates the severity of depressive symptoms (Clarke, 2009), complicating the management of both physical and mental health conditions (Morris, et al., 2012). Reports from the World Health Organization indicate that of any chronic disease, depression produces the greatest diminution of overall personal health and, as a coexisting condition, is more debilitating.
than any other disease combination contributor (Moussavi, et al., 2007). The prevalence of depression is reported anywhere from three to five times higher among complex patients than the general population (Bair, Robinson, Katon, & Kroenke, 2003; Teh, Reynolds, & Cleary, 2008). Additionally, physical illness can disguise the symptoms of depression since some symptoms are common to both physical and mental disorders, complicating the assessment of depression (NICHE, 2009).

Furthermore, diagnostic decisions, depression treatment adherence, and symptom improvement are further complicated by the economic, socio-cultural, and environmental factors often experienced by individuals with lower socioeconomic status (SES) (Alegria, et al., 2008; Everson, Maty, Lynch, & Kaplan, 2002; Lorant, et al., 2003). For example, studies show higher odds of persisting depression (Lorant, et al., 2003), and lower rates of service use for depression (Alonso, et al., 2004) among low SES populations. Given most patients (particularly low SES populations) with poor mental health and coexisting illnesses are cared for in primary care settings (Arnow, et al., 2006), developing and targeting more effective interventions for primary care settings is critical for reducing disparities in the diagnosis and treatment of depression, especially for low-income primary care patients with limited access to mental healthcare.

Providing adequate behavioral health treatment in primary care is challenging, especially for medically indigent populations suffering from poorer mental and physical health. Even when depression recognition is adequate for low-SES populations, gaps remain in the quality of the depression care and in the understanding of how the patients’ competing life demands interplay with depression care and improved symptomatology. Research related to improving behavioral health treatments and interventions for medically indigent complex patients are not only a research priority, but also a clinical imperative. Fortunately, there is evidence that treating depression in patients with chronic physical health problems can potentially increase life expectancy and their overall quality of life (NICHE, 2009); however, we lack understanding about how the severity of chronic illnesses moderates the effect of depression treatment on
symptom improvement (Teh, et al., 2008), particularly for patients who are medically indigent and economically disadvantaged.

The purpose of this two-phase sequential mixed methods study was two-fold: examine the potential relationship between coexisting illness severity and change in depression over time; and to identify contextual factors that influence beliefs, attitudes, and treatment preferences for depression and coexisting illness care for primary care patients experiencing a new episode of depression. This study will build upon the findings of a randomized control trial (RCT) that trained primary care providers in a communication strategy to improve clinical dialogue around depression (Keeley & Brody, 2012). The setting for the study was an integrated safety-net health care network called Denver Health and Hospital Authority (DHHA) in Denver, Colorado that primarily treats economically-indigent patients. Though existing research has identified the adverse effect of chronic illness on depression symptom improvement, gaps remain in understanding how the severity of chronic illnesses-as well as patients’ competing demands-interplay with depression care and improved symptomatology.

**Study Purpose and Rationale**

**Research Questions**

Given the lack of evidence concerning the potential relationship between physical illness severity and depression symptom improvement, as well as the patient narrative around living with depression and coexisting illnesses, this dissertation addressed the following research questions:

1. Does the severity of coexisting medical illnesses impact depression symptom improvement for primary care patients experiencing a new episode of depression?
2. How do complex depression patients describe their lived experience with concurrent illnesses?
3. How does a diagnosis of a new episode of depression impact the management and prioritization of concurrent illnesses for complex patients?
Influenced by the model of competing demands—particularly patient-level demands—(Jaen, Stange, & Nutting, 1994), I hypothesized that patients with high competing illness severity would experience significantly less depression symptom improvement over time.

**Specific Aims**

Specifically, this dissertation research addressed the following aims:

**Aim 1**
Determine whether severity of coexisting illnesses were associated with improvement of depressive symptom outcomes for moderately to severely depressed primary care patients with coexisting illnesses (complex patients).

**Aim 2**
Identify how patients perceive the “bi-directional” relationship between depression and physical illness.

**Aim 3**
Describe the effects of illness complexity on patient’s quality of life including, but not limited to, physical and social functioning.

**Aim 4**
Describe the contextual factors (competing demands) that influence complex patients’ beliefs, attitudes, and treatment preferences in receiving care for their depression and coexisting illnesses in a primary care setting.

**Overview of the Research Methods**

This mixed-methods study used a combination of quantitative analysis of secondary data, as well as in-depth qualitative interview data to address the study aims (FIGURE I.1). For the quantitative analysis, I used Hierarchical Linear Modeling (HLM) to examine the association between the number and severity of coexisting medical illnesses and depression symptom improvement, over time, for complex patients with a major depressive disorder (MDD) in a clinical trial study. For the qualitative analysis, I conducted a thematic analysis of semi-structured interviews. I selected a mixed-method design because it provided a way to place statistical findings in context, allowing for a rich explanation of related phenomena (Johnson & Onwuegbuzie, 2004).
Study Setting and Participants

This secondary analysis used data from 168 patients screened for depression from eight primary care health clinics in the Denver Health system that provide health care services to low-income and underinsured people (medically indigent) in Denver, Colorado. Patients were enrolled in Medicare, Medicaid or the Colorado Indigent Care Program (CICP) or both, and of various race/ethnicities, and at least 18 years of age. For the qualitative interviews, and given the intent to understand the potential effect of comorbid illnesses on depression symptom improvement, purposeful sampling techniques were used to identify patients with low, medium and high illness severity, and with increased, neutral and decreased depression symptom improvement at 6-12-, and 36-weeks after baseline.
**Significance of the Study**

A review of the literature on treating depression in primary care highlights that although the impact of coexisting illness on depression symptom improvement has been examined, most studies have focused on either the impacts of antidepressant medications (Koike, et al., 2002; Kurdyak & Gnam, 2004; Lin, et al., 2012), isolating only one co-existing chronic illness for comparison (e.g., cancer, diabetes), or included a sample consisting of only older adults, or all or some of the above (Iosifescu, 2007) (all relevant studies are reviewed in Chapter II).

Additionally, a disproportionate number of the studies used a simple count of morbidities, which may not reflect severity of symptoms or the chronicity of specific illnesses, which are limitations when assigning equal weight to all illnesses. A more nuanced approach was to assess the severity of each illness (Fortin, Bravo, Hudon, Vanasse, & Lapointe, 2005; Huntley, Johnson, Purdy, Valderas, & Salisbury, 2012). Thus, a primary aim of this dissertation was to test whether severity of coexisting illnesses are associated with improvement of depressive symptom outcomes among moderately to severely depressed medically-indigent primary care patients ages ≥18 participating in a non-pharmaceutical treatment focused on improving clinical dialogue around depression delivered by primary care providers (PCPs). Improving our understanding the pathways through which coexisting illnesses influence depression symptom improvement in primary care is imperative. From a clinical perspective, complex patients (patients with multiple chronic medical conditions occurring simultaneously) represent the major users of health care services in the U.S. accounting for more than two-thirds of health care spending (Tinetti, Fried, & Boyd, 2012). Furthermore, depression as a coexisting illness with the more prevalent chronic disorders (e.g., coronary heart disease, diabetes) is associated with poor self-care, and increased complications (Katon 2010), which can lead to more severe illness severity and earlier death. Thus, the identification of effective interventions to treat patients with multiple conditions, particularly, the coexistence of physical and psychological disorders, is timely and important.
A second aim of this dissertation was to collect in-depth qualitative data from semi-structured interviews to identify specific contextual factors (e.g., competing demands) that influence patients’ beliefs, attitudes, and treatment preferences for their depression and coexisting illness care. Though competing demands at the provider-level have been previously explored (Jaen et. al., 1994; Nutting et.al., 2008; Rost et. al., 2000; Stange et.al., 1994), less understood are the competing demands at the patient-level (e.g., financial strain, poor living conditions, co-occurring illnesses), and what those demands mean for chronic illness care and depression symptom improvement. A third aim was to explore how patients perceive the relationship between depression and chronic physical illness, specifically which, between depression and chronic illness, patients prioritize as crucial for immediate care. Though coexisting depression and chronic illness is common, it is not satisfactory to conclude that they have a linear relationship, but in fact a more complex, bi-directional one, where depression influences chronic illness severity and treatment, or vice versa. A conceptual model including descriptions of the three phases, along with sampling strategies, brief descriptions of the quantitative and qualitative methods, and how they associate with each of the aims is included below (FIGURE I.2).
Description of Original Study (Keeley, 2012)

- Previously recruited from provider’s current list of patients.
- Recruited by telephone.
- All patients completed the Patient Health Questionnaire-2 during initial telephone call.
- Informed consent and baseline data collected prior to visit in clinic waiting areas.

PHASE I (Secondary Data)

- n=168
- Score each patient’s coexisting illness severity using the Cumulative Illness Rating Scale (CIRS)

PHASE II

- Test for the potential effect of coexisting illness severity on depression symptom improvement

Quantitative (Specific Aim 1)

- Using HLM, examine whether or not the patient’s CIRS score at baseline predicted depression symptom improvement over time

PHASE III (Primary Data)

- n=19
- Telephonic, semi-structured interviews with purposefully selected patients to better understand their lived experience with a new episode of depression as well as their beliefs about the relationship between depression and coexisting illnesses

Qualitative (Specific Aims 2, 3, & 4)

- Criterion sampling based on baseline CIRS score; stratified purposeful sampling varying on four parameters: CIRS score, PHQ-9 score, gender, and intervention/control.
- Iterative process including review of the question guide and script
- Data analyzed using ATLAS.ti.

FIGURE I.2: Structure of the Dissertation
Terminology

Given the number of terms used in this study and the complexity of some of those terms, definitions of the various terms along with citations are included to improve understanding. These citations include existing studies published in peer-reviewed academic journals, the Diagnostic and Statistical Manual IV (DSM-IV) published by the American Psychiatric Association, the Centers for Disease Control and Prevention (CDC), and the National Institutes of Mental Health (NIMH). A glossary of terms (Appendix A) is included with the definitions of terms central to this study.

The DSM-IV offers a series of symptoms associated with depressive disorder including depressed mood most of the day (e.g., feeling sad or empty), “markedly diminished” pleasure or interest in most daily activities including those activities necessary to maintain manageable living conditions (e.g., employment, family and other social interactions), change in sleep patterns, lack of energy and capacity to concentrate (e.g., reading, watching television), and “recurrent” thoughts of hurting oneself or suicidal ideation with or without a specific plan (American Psychiatric Association, 2000). For the purposes of this study, the term depression is used to refer to a mental health condition that meets diagnostic criteria such as those published in the DSM-IV.

Though major depressive disorder (MDD) is typically reported as a dichotomous variable (YES or NO), this study aims to measure improvement in depressive symptoms necessitating a continuous measure instrument. While acknowledging that MDD can be difficult to quantify or interpret uniformly across populations of different socioeconomic status, cultural traditions, and communities, there are several instruments for detecting MDD the aimed at accurately assessing an individual’s mental health status. The study assumed that distinctions exist in the severity of depression (Aim 1) critical to fully understanding not only the current depressive state of each patient, but to better assess the effectiveness of depression interventions at multiple levels of depressive states. Specifically, depression was given diagnostic scores listed as moderate (10-
14), moderately severe (15-19), and severe (≥ 20) depression in accordance with a 9-item depression module called the Patient Health Questionnaire-9 (PHQ-9) (Kroenke, Spitzer, & Williams, 2001). The PHQ-9 is a questionnaire that assesses depressive symptom criteria in accordance with the symptoms described in the DSM-IV including “little interest in doing things”, “feeling down or depressed”, “trouble concentrating”, and “thoughts that you would be better off dead or hurting yourself in some way” (Kroenke, et al., 2001). As a measure of depression severity, the PHQ-9 scores range from 0-27 with each of the nine items having possible individual scores of 0 (not at all) to 3 (nearly every day). A copy of the PHQ-9 is included in the appendix.

I used the term comorbidity in this research as an encompassing term to refer to both physical and mental health conditions and is defined as “the presence of more than one distinct (health) condition in an individual” (Valderas, Starfield, Sibbald, Salisbury, & Roland, 2009). Comorbidity can often be either the cause or the consequence of an index disease and can affect disease detection, therapy, and desired outcomes or changes to behavior (de Groot, Beckerman, Lankhorst, & Bouter, 2003). Additionally, evidence suggests that comorbid illnesses affect the effectiveness of treatments and interventions. For the purposes of my research, comorbidity was counted, weighted, and reported by severity of the illnesses using the Cumulative Illness Rating Scale (CIRS) which rates comorbidity on a five-point severity scale based on 13 anatomical domains (e.g., cardio-vascular respiratory system, neurological etc.), making it a methodological superior approach to measuring comorbidity to using strictly a simple count.

This study used complex patient as a term to refer to those patients with multiple chronic conditions that often require unique services and care management strategies (Bayliss, Ellis, & Steiner, 2005; Fortin, Soubhi, Hudon, Bayliss, & van den Akker, 2007). Complex patients can experience adverse health outcomes, higher healthcare costs, as well as a decreased quality of life, and psychological distress (Bayliss, Edwards, Steiner, & Main, 2008; Bayliss, et al., 2005; Fortin, Soubhi, et al., 2007; Newcomer, Steiner, & Bayliss, 2011).
This study used several descriptors to refer to social issues and stressors experienced by the patient populations. The term *socially and economically disadvantaged* is used as an encompassing term to describe individuals and groups experience conditions of poverty, inadequate resources, and deprivation, as well as limited political capital and “unequal access to opportunities, social rewards, and social status” (Centers for Disease Control and Prevention, 2011c; U.S. Department of Health and Human Services, 2001). This study included patients that are *socially and economically disadvantaged* with limited access to health services along with transportation issues, language barriers, or other issues hindering adequate medical care and are referred throughout this research as *medically-indigent*.

Lastly, this study referred to providers as *Primary Care Providers (PCPs)*, which includes nurse practitioners, family doctors, physician’s assistants, and internists. Specific titles are delineated when necessary.

**Structure of the Dissertation**

This dissertation follows a six-chapter format and includes a Table of Contents, List of Tables and Figures, Glossary of Terms, Appendices, and a List of References. Following this introduction (Chapter 1), Chapter 2 discusses related literature supporting the study’s aims, as well as health and social theories supporting the study’s hypotheses, methodology, and interpretation of the results. Chapter 3 outlines the research methods and design used for data collection (both quantitative and qualitative respectively), the analysis of the findings, and methods to verify the findings. The results are presented in Chapters 4 (Quantitative) and 5 (Qualitative). Chapter 6 summarizes and concludes the study by discussing the findings relative to existing literature, the identified theoretical concepts (both introduced in Chapter 2), implications of this work, study limitations, and how the findings contribute to the current body of knowledge, as well as suggestions for future research.
CHAPTER II

REVIEW OF THE LITERATURE

In the United States, mental disorders are common, and often serious, significantly impacting the population. In 2010, the Substance Abuse and Mental Health Services Administration (SAMHSA) estimated 45.9 million adults (ages 18 and older) had a mental illness\(^1\), representing 20% of the total U.S. adult population (Substance Abuse and Mental Health Services Administration (SAMHSA), 2012). Globally, mental illnesses account for more than 11% of disease burden (Ustun, Ayuso-Mateos, Chatterji, Mathers, & Murray, 2004), with that number increasing to 15% for developed nations, including the United States (Murray & Lopez, 1996). Depression disorders\(^2\) in particular can result in serious impairment and societal costs (Katon, 2009; Substance Abuse and Mental Health Services Administration (SAMHSA), 2012).

The economic toll depression has in the United States is estimated at over $83 billion annually, of which $52 billion are attributed to workplace costs including absenteeism or productivity impairment (Greenberg & Birnbaum, 2005). The intrapersonal toll of depression includes continuous feelings of diminished interest in previously enjoyed activities, recurring feelings of guilt, chronic fatigue, difficulties concentrating, sleep disorders, weight gain or loss, and recurrent thoughts of inflicting pain on oneself and/or suicide (Centers for Disease Control and Prevention, 2011a). Both the World Health Organization *International Classification of Diseases* (ICD-10) and the American Psychiatric Association *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) list criteria for depression with some general agreements on the etiology of the disorder (TABLE II.1).

---

\(^1\) Mental Illness is defined as currently or at any time in the past year having a diagnosable mental, behavioral, or emotional disorder (excluding substance abuse) of sufficient duration to meet diagnostic criteria specified within the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association).

\(^2\) Major depressive disorder will be referred to as “depression” in this chapter.
TABLE II.1: Diagnostic Criteria for Depression/Depressive Disorder from the World Health Organization ICD-10 (WHO, 1990) and the American Psychiatric Association DSM-IV (APA, 2000)

<table>
<thead>
<tr>
<th>Clinical significance</th>
<th>ICD 10 Depressive disorder</th>
<th>DSM-IV Major depressive disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Some difficulty in continuing with ordinary work and social activities, but will probably not cease to function completely in mild depressive episode; considerable distress or agitation, and unlikely to continue with social, work, or domestic activities, except to a very limited extent in severe depressive episode</td>
<td>Symptoms cause clinically significant stress or impairment in social, occupational, or other important areas of functioning</td>
</tr>
<tr>
<td>Duration of symptoms</td>
<td>A duration of at least 2 weeks is usually required for diagnosis for depressive episodes of all three grades of severity</td>
<td>A major duration of the day, nearly every day, for at least 2 weeks</td>
</tr>
<tr>
<td>Severity</td>
<td>Depressed mood, loss of interest and enjoyment, and reduced energy leading to increased fatigue and diminished activity in typical depressive episodes; other common symptoms are:</td>
<td>Five or more of the following symptoms; at least one symptom is either depressed mood or loss of interest or pleasure:</td>
</tr>
<tr>
<td></td>
<td>(1) Reduced self-esteem/self-confidence</td>
<td>(1) Depressed mood</td>
</tr>
<tr>
<td></td>
<td>(2) Reduced concentration and attention</td>
<td>(2) Loss of interest</td>
</tr>
<tr>
<td></td>
<td>(3) Recurring feelings of guilt and unworthiness</td>
<td>(3) Significant weight loss or gain or decrease or increase in appetite</td>
</tr>
<tr>
<td></td>
<td>(4) Bleak and pessimistic views of the future</td>
<td>(4) Insomnia or hypersomnia</td>
</tr>
<tr>
<td></td>
<td>(5) Suicidality/self-harm</td>
<td>(5) Psychomotor agitation</td>
</tr>
<tr>
<td></td>
<td>(6) Not enough or too much sleep</td>
<td>(6) Fatigue or loss of energy</td>
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<td>(7) Change in appetite</td>
<td>(7) Feelings of worthlessness or excessive or inappropriate guilt</td>
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<td>(8) Recognizable changes in speech</td>
<td>(8) Diminished ability to think or concentrate</td>
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<td></td>
<td>For <em>mild depressive episode</em>, 2 of most typical symptoms of depression and of the other symptoms are required</td>
<td>(9) Recurring Suicidality/self-harm</td>
</tr>
<tr>
<td></td>
<td>For <em>moderate depressive episode</em>, 2 of 3 of most typical symptoms of depression and at least 3 of the other symptoms are required.</td>
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<tr>
<td></td>
<td>For <em>severe depression episode</em>, all 3 of the typical symptoms noted for mild and moderate depressive episodes are present and at least 4 other symptoms of severe intensity are required</td>
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</table>

Adapted from Gilbody (2011)

In the US, chronic conditions, which require ongoing treatment and self-management, are the most commonly seen in health care settings (Grumbach, 2003; Ridgeway, et al., 2014) and are responsible for nearly 70% of all mortality affecting approximately 133 million adults (National Center for Chronic Disease Prevention and Health Promotion, 2012). The rate of people living...
with chronic conditions is increasing faster than originally predicted, supporting the critical need
for more research around improving chronic care. In 2010, approximately 75 million people in
the U.S. fit the definition of *complex patients*, defined as having multiple (two or more)
coexisting chronic illnesses, conditions of “long duration” and characterized by “ongoing
medical attention and/or limit activities of daily living” (Eton, et al., 2015; Parekh & Barton,
2010; Warshaw, 2006; World Health Organization, 2013). Chronic illnesses are costly,
accounting for nearly 65-80% of total national health care expenditures in the U.S., (Anderson,
2010; Guthrie, 2014; Parekh & Barton, 2010; Robert Wood Johnson Foundation, 2010; Ward,
Schiller, & Goodman, 2014), and contribute an undue individual medical burden by decreasing
quality of life, increasing levels of psychological distress, and social deprivation (Creed, et al.,
2002; Fortin, Bravo, Hudon, Lapointe, Almirall, et al., 2006; Fortin, Bravo, Hudon, Lapointe,
Dubois, et al., 2006; Fortin, Soubhi, et al., 2007).

The bi-directional effects of depression and chronic illness are well documented with
depression contributing to the development and progression of various physical illnesses, and
physical illnesses increasing the risk of depression (Steptoe, 2007). Depression is prevalent
among patients with competing chronic illnesses and adversely impacts self-care (e.g., patient
initiated behaviors like exercise, diet, medication adherence) of chronic disease resulting in
increased resource utilization (e.g., expensive secondary care referrals) (Gilbody, 2011; Guthrie,
2014). Depression in people with coexisting illnesses impairs functioning by (1) amplifying
reactions to somatic symptoms; (2) reducing motivation to care for physical ailments; and (3)
limiting the energy, and cognitive capacity to cope with physical illness while increasing
subjective senses of shame or social stigma (Creed & Dickens, 2006; Creed, et al., 2002;
Martucci, et al., 1999). The prevalence of depression coexisting with other chronic conditions is
staggering, a problem compounded by the fact that depression is “rarely detected and treated
adequately in people who have physical illness” (Creed & Dickens, 2006, p. 3). Though
evidence-based treatments for depression are available and have been shown to improve
depressive symptoms for the chronically ill, many, if not most, complex patients continue to suffer from untreated depression.

Further complicating the deleterious effects of coexisting depression and chronic physical illness are economic disadvantages, which are associated with the initial onset of depression symptoms and worse prognosis (Gilman, Kawachi, Fitzmaurice, & Buka, 2002; Gilman, Trinh, et al., 2013). Although mental illness is a ubiquitous problem affecting all races and ethnicities (U.S. Department of Health and Human Services, 2001), economic and social disadvantages magnify the consequences of mental illnesses, and limit access to adequate care, leading to mistrust of the medical system (Alegria, et al., 2002; Alegria, et al., 2008; Smedley, Stith, & Nelson, 2003; U.S. Department of Health and Human Services, 2001). One way that mental illness compounds a person’s economic status is the additional health costs that accrue, including estimates showing between a 33 to 170 percent increase in monthly medical costs for complex patients with a psychological disorder (e.g., depression and/or anxiety) (Guthrie, 2014; Melek & Norris, 2008). Being economically disadvantaged is also linked to reduced access to mental health treatment, and poorer clinical depression outcomes. (Gilman, Bruce, et al., 2013; Gilman, Fitzmaurice, et al., 2013). Potentially, the relationship between being economically disadvantaged and poorer mental health is mediated by chronic exposure to adverse life situations (e.g., unemployment, low wages, housing conditions), and little or no social support (Clarke, 2009; Clarke & Currie, 2009; Wilhelm, Mitchell, Slade, Brownhill, & Andrews, 2003). The World Federation for Mental Health (2012) identified additional risk factors for depression such as low education level and exposure to violence, which is more prevalent in economically disadvantaged populations.

The problems faced by patients with depression and chronic illness have highlighted the need for research to address issues around (1) access to adequate mental health care, (2) equity of access to distribute mental health care, and (3) the effectiveness of mental health services including better collective management of mental illnesses and eliminating inappropriate
allocation and use of psychotropic medications (Gilbody, 2011). Concurrently, the U.S. Department of Health and Human Services identified areas to address including cultural, social, and economic factors contributing to mental health care disparities including stigma, poverty, and the overall financing of services (U.S. Department of Health and Human Services, 2001), along with integrating mental health services into primary care (Galson, 2009). Consistent with these recommendations, this dissertation research explored the potential effect coexisting illness severity has on depression symptom improvement in economically disadvantaged primary care patients using secondary data from a completed RCT on depression treatment (Keeley & Brody, 2007).

The following background sections include a review what is known about the connection between chronic health conditions and depression, delivery of behavioral health services in primary care, challenges in caring for medically- and economically-indigent complex patients with depression, the complications faced by primary care providers caring for medically- and economically-indigent complex patients, as well as the theoretical assumptions guiding the study’s methodology.

**Chronic Illness and Depression among Medically-Indigent Populations in Primary Care**

Given the increased susceptibility to mental disorders, lack of access to mental health resources, and numerous barriers to care, developing and implementing strategies to better manage depressive disorders for economically- and medically-indigent\(^2\) individuals is a public health imperative. One setting that can have a significant impact on mental health disparities seen in populations of low socioeconomic status (SES) is primary care. However, the barriers to adequate detection and treatment of depression in primary care can be challenging for PCPs caring for socially and economically disadvantaged; disadvantages typically associated with

\(^2\) Some of the literature on medically-indigent populations only includes those individuals with no health insurance or means to pay for health care. For the purposes of this study, “medically-indigent” will include those individuals enrolled in safety-net programs for indigent populations including but not limited to MEDICAID.
poorer access to care and limited health care resources including little or no health insurance (i.e., medically-indigent) (Bovbjerg & Kopit, 1986).

Health outcomes follow SES gradients related to socioeconomic status (SES) from those living in poverty to those individuals with relatively high SES with the most affluent having better health outcomes compared to the less advantaged (Glazier, Agha, Moineddin, & Sibley, 2009; Macintyre, 1994; Pickett & Pearl, 2001). The relationship between chronic disease prevalence and SES is clear, as is the correlation between SES and the risk factors for chronic disease (Adler & Ostrove, 1999). Low SES is associated with increased risk for multiple health problems leading to an increase risk in premature morbidity and mortality (Inglis, Ball, & Crawford, 2005; Lantz, et al., 1998; Marmot, Kogevinas, & Elston, 1987; Pampel, Krueger, & Denney, 2010; Stringhini, et al., 2010). Economically disadvantaged populations not only suffer disproportionally from adverse health outcomes and behaviors (Stringhini, et al., 2010; Walsh, Seen, & Carey, 2013) but concurrently face personal and contextual barriers to successful treatment of those diseases (Mansyur, Pavlik, Hyman, Taylor, & Goodrick, 2013).

Existing research suggests psychosocial factors have an impact on mental disorders (e.g., depression) even after controlling for genetic factors (Piccinelli & Wilkinson, 2000; Stansfeld & Rasul, 2006). Individuals in the lower socioeconomic strata (i.e., poverty) experience significantly higher rates of psychological stress and mental disorders including depression (Akhtar-Danesh & Landeen, 2007; Hudson, Neighbors, Geronimus, & Jackson, 2012; Kohn, Dohrenwend, & Mirotznik, 1998; Piccinelli & Wilkinson, 2000; Saraceno, Levav, & Kohn, 2005). In 2010, The Office of Minority Health reported “adults living below the poverty level (as determined using the U.S. Census Bureau computations) were three times more likely to have serious psychological distress as compared to adults over twice the poverty level” (The Office of Minority Health, 2013).

The predominance of mental disorders, especially depressive disorders, among people of lower SES has been hypothesized to be explained by financial disadvantages, high rates of
unemployment (Mossakowski, 2008), limited educational opportunities and low standard of living (Stansfeld & Rasul, 2006), all demonstrated to have proximal effects on risk for depression. Exacerbating these disparities for less affluent populations are lower access and availability of mental health services (U.S. Department of Health and Human Services, 2001) for certain racial/ethnic groups. Recent reports demonstrate the reduced utilization rates and adherence to mental health treatment for black and Latino groups in rates, noting that the needs of minority racial/ethnic groups remain unmet (Chow, Jaffee, & Snowden, 2003; U.S. Department of Health and Human Services, 2001; US Department of Health and Human Services, 1999).

Although the relationship between racial/ethnic populations, low SES, and mental health utilization is complex, several factors are clear:

- Poorer communities inhabited by historically marginalized racial/ethnic groups do not have the community resources to recognize and treat mental health (Chow, et al., 2003; U.S. Department of Health and Human Services, 2001);

- Patients may expect mistreatment due to perceived discrimination and prejudice (Wang, et al., 2005);

- Patients may not trust the medical system (Katon, 2003); and

- Provider-level factors including competing demands, insufficient reimbursement protocols for mental health care, and inadequate training and experience treating mental health disorders are exacerbated in poorer communities (Klinkman, 1997; Nutting, et al., 2000; Wang, et al., 2005).

Figure II.1 illustrates the relationships between those levels and how they potentially hinder depression symptom improvement, including the potential relationship posed by patients not receiving adequate care on the overall health care system (e.g., increased cost, increased emergency room visits).
Addressing system-, provider-, and patient-level factors contributing to health outcomes of medically-indigent populations, including the Medicaid populations, becomes even more important with recent legislation projects expanding Medicaid coverage to 15 million more people by 2019 (National Association of Community Health Centers, 2010).

FIGURE II.1: Factors Contributing to Depression Outcomes in Primary Care
Medical Illness Comorbidity and Depression

A substantial amount of evidence demonstrates that individuals with psychological disorders (e.g., depression) are disproportionately affected by chronic disease, often contributing to poorer outcomes for both chronic disease management and mental health improvement (Benton, Staab, & Evans, 2007). Concomitant physical and mental illnesses are associated with poor treatment (both physical and psychological) response, lost work productivity, occupational disability, lower reported quality of life, increased participation in health compromising behaviors, and increased healthcare costs (Benton, et al., 2007; Gonzales, et al., 2011; Iosifescu, 2007; Katon, 2003; Pagoto, 2011; Steptoe, 2007). Though research suggests the existence of a bi-directional relationship between depression and chronic illness, understanding the contextual and latent factors that make up the relationship is imperative to improve both physical and psychological health outcomes.

Recently, research on the relationship between depression and physical illness has increased, along with interventions designed to improve depression recognition and treatment for PCPs. However, these studies did not aim to understand the potential bi-directional relationship between chronic illness and depression, focusing rather on depression as a cause and/or consequence of a chronic illness, as well as depression being associated with poor outcomes of medical illness and increased mortality (Iosifescu, 2007). Examples of this unidirectional relationship include depression caused by obesity (Clark, Cargill, Medeiros, & Pera, 1996; Linde, et al., 2004; Pagoto, et al., 2007), type 2 diabetes (Anderson, Freedland, Clouse, & Lustman, 2001; Black, Markides, & Ray, 2003; de Groot, Anderson, Freedland, Clouse, & Lustman, 2001; Katon, et al., 2005; Zhang, et al., 2005), cardiovascular disease, a disease that depression independently predicts (Barth, Schumacher, & Herrmann-Lingen, 2004; Kronish, Rieckmann, Schwartz, Schwartz, & Davidson, 2009; van Melle, et al., 2004), and cancer (Spiegel & Giese-Davis, 2003). Since understanding the association between depression and the overall burden of comorbid medical illness is critical, an equally important area of research pertains to the course of
depression in complex patients. Though Benton and colleagues (2007) as well as Pagoto (2011) have extensively studied the relationships between psychiatric illness and physical illness, this dissertation includes a review of some of those findings with concentration on relevant illnesses seen in the population recruited for this study.

**Prevalence of Depression Comorbid with Specific Medical Illnesses**

A large body of literature describes the prevalence of depression among complex patients in primary care. Most of the studies look at the relationship between depression and one particular chronic disease, primarily the most common illnesses seen in primary care (i.e., obesity, type II diabetes, and chronic pain). The studies identified as relevant to this dissertation research are described below to demonstrate the coexistence of depressive disorders and chronic medical illness.

The prevalence of obesity in patients with diagnosed psychiatric illnesses has rapidly increased compared to the general population (Allison, et al., 2009). Obese individuals not only suffer disproportionately from psychiatric illnesses, but obesity appears to be a risk factor for various mental problems like depression (Pagoto, et al., 2011). The association between depressive disorders and obesity is shown in both epidemiological and clinical studies. Simon and colleagues using a U.S. representative sample showed a significantly higher percentage of obese adults met the criteria for depression compared to their non-obese counterparts (Simon, et al., 2006). One important finding from studies on obesity and depression is the relationship between increasing degrees of obesity with increasing severity of depression. Psychological factors could potentially explain the association between obesity and depression. Given the association of depression and obesity, assessments of depression for obese individuals in clinical settings (e.g., primary care) should be part of standard care, especially given depression could contribute to further weight gain, as well as patient decision making around weight loss treatments, and patients’ confidence for weight loss success and management. Though
antidepressant medication treatment options are available for obese patients with depressive symptoms, psychotropic medication has been linked as a residual contributor to the growing obesity epidemic in the U.S., given weight gain is a side effect of antidepressants, which can lead to medication noncompliance (McAllister, et al., 2009), and further psychological frustration felt by the patient.

Type 2 diabetes (T2DM) continues to be a major public health problem estimated to affect more than 435 million adults worldwide, and a 20% increase is projected in developed nations over the next 20 years (Gonzales, et al., 2011). Optimal treatment for T2DM is significantly dependent on patient behavior (lifestyle factors like diet and exercise) and treatment adherence to blood glucose monitoring, and prescribed medications related to their counterparts without depression. Individuals with T2DM commonly show symptoms of depression and distress, which has been associated with poorer treatment adherence and increased mortality (Black, et al., 2003; Gonzalez, et al., 2008). Furthermore, depression and diabetes mellitus seem to have a bi-directional relationship, with depression symptoms preceding the development of diabetes (Gonzales, et al., 2011; Knol, et al., 2006) and with development of T2DM followed by an increase in depressive symptoms (Bogner, Morales, de Vries, & Cappola, 2012). Though available literature does not offer definitive evidence of biological pathways mediating the relationship between diabetes and depression, it does show that the health compromising behaviors (HCBs) often associated with the development of T2DM are prevalent in those individuals either clinically diagnosed with depression or exhibiting depressive symptoms. These HCBs include tobacco use, poor diet, lack of physical activity, and medication non-adherence (Gonzales, et al., 2011; McClave, et al., 2009). Additionally, while pharmacological interventions for depression have been recommended for patients with diabetes (including T2DM) (Goodnick, 2001; Lustman, et al., 2000), antidepressant medications frequently lead to undesired side effects including weight gain and hyperglycemia both serious complications for patients with diabetes (Gonzales, et al., 2011).
Chronic pain continues to be one of the most commonly seen medical conditions in primary care, and ranks as the 3rd most prevalent complaint for all primary care visits (Upshur, Luckmann, & Savageau, 2006; Van Dorsten & Weisberg, 2011). Adding to the burden of pain are the feelings of depression commonly associated with chronic pain (Fishbain, Cutler, Rosomoff, & Rosomoff, 1997). The symptoms of depression (e.g., loss of pleasure in everyday activities, sadness, hopelessness, and fatigue) are often the residual effect of persistent pain, and of debilitating episodes experienced regularly by patients with chronic pain (Van Puymbroeck, Zautra, & Harakas, 2006). The strong association between pain and depression also contributes to adverse immune functioning critical to physical and mental illness improvement. Literature on illnesses coexisting with depression identifies pain as the most frequently seen concomitant complaint (Van Dorsten & Weisberg, 2011), with some rates as high as 30-56% of patients with depression. Concurrently, patients with depression experience symptoms of pain more than patients with cardiac disease, cancer, diabetes, and neurological disorders (Campbell, Clauw, & Keefe, 2003; Van Dorsten & Weisberg, 2011; Van Puymbroeck, et al., 2006; Von Korff & Simon, 1996).

**Studies comparing depression treatment outcomes for patients with and without coexisting illnesses**

Some of the studies on the relationship of coexisting illness with depression symptom improvement focused on the effects of comorbidity on antidepressant medication tolerance and adherence (Iosifescu, et al., 2003; Koike, et al., 2002; Oslin, et al., 2002; Papakostas, et al., 2003; Perlis, et al., 2004). Of those, two studies had an open-label design using one single antidepressant (Iosifescu, et al., 2003; Papakostas, et al., 2003), one looked at a single antidepressant (Perlis, et al., 2004), and three looked at different antidepressant medications to test for rates of prescription use and adherence (Koike, et al., 2002; Oslin, et al., 2002; Simon, Von Korff, & Lin, 2005).
Six additional studies examined the differences in response to depression care interventions between individuals with depression and coexisting chronic illnesses (Bogner, et al., 2005; Duhoux & et. al., 2009; Harpole, et al., 2005; Koike, et al., 2002; Morris, et al., 2012; Vera, et al., 2010). Teh and colleagues (2008) evaluated the effect of chronic medical conditions on depression diagnosis and care, including outcomes related to depression diagnosis, patient satisfaction, patient/provider communication and continuity of care. The instruments used to measure depression in these studies included the Composite International Diagnostic Interview (Short-Form, and standard versions) (Kurdyak & Gnam, 2004; Teh, et al., 2008), Hamilton Rating Scale for Depression (Bogner, et al., 2005; Iosifescu, et al., 2003; Morris, et al., 2012; Papakostas, et al., 2003; Perlis, et al., 2004), Centers for Epidemiological Studies Depression scale (CES-D) (Koike, et al., 2002), mental component score of the Short-Form 12 (Harpole, et al., 2005), Structured Clinical Interview for DSM-IV/Hopkins Symptom Checklist (Simon, et al., 2005; Vera, et al., 2010), Geriatric Depression Scale (Oslin, et al., 2002), and the Patient Health Questionnaire-2 and -9 (Katon, et al., 2010; Vera, et al., 2010). The strategies/instruments to measure medical illness varied by study and included noting the presence of medical illness (Koike, et al., 2002), survey data completed by patients (count of medical illness) (Harpole, et al., 2005; Kurdyak & Gnam, 2004; Morris, et al., 2012; Oslin, et al., 2002; Teh, et al., 2008; Vera, et al., 2010), the Cumulative Illness Rating Scale (CIRS) which classifies comorbidities by organ system along with the severity of each illness (Iosifescu, 2007; Papakostas, et al., 2003; Perlis, et al., 2004), the Charlson Comorbidity Index (Bogner, et al., 2005), and computerized chart reviews of existing medical illness (Katon, et al., 2010; Simon, et al., 2005).

Differences among the study designs and interventions make comparisons of their findings difficult. For example, four of the studies found that coexisting illness had little or no effect on depression remission and symptom improvement (Bogner, et al., 2005; Harpole, et al., 2005; Papakostas, et al., 2003; Perlis, et al., 2004). Of those studies, two (Papakostas, et al., 2003; Perlis, et al., 2004) included only patients who had treatment-resistant depression and had small
sample sizes (n=101 and n=92) limiting their ability to detect a difference. Two of the studies (Iosifescu, et al., 2003; Koike, et al., 2002) showed that comorbid medical disorders had an impact on depression symptom improvement for both antidepressant and behavioral interventions. Iosifescu et al. (2003) investigated the role of comorbid medical illness on severity of depression and antidepressant outcomes in depressed patients, hypothesizing that patients with depression would experience more severe symptoms of depression which would lead to lower rates of treatment response (≥50% reduction in depression score) and remission (score ≤7 for depression score at the end of the trial) compared to patients with depression but no medical comorbidity. The sample consisted of 384 outpatients meeting DSM-III-R criteria for depression, enrolled in an 8-week open treatment with fluoxetine. Using the CIRS to measure comorbidity, the authors concluded that the total burden of medical illness (CIRS overall score) and the number of organ systems affected response to fluoxetine treatment and clinical remission. Additionally, patients with higher burden of medical comorbidity had significantly higher depression scores at the end of the 8-week treatment, showing that “medical comorbidity can have a significant negative impact on outcome of acute treatment of depression” (p. 2125).

Koike, Unutzer, and Wells (2002) examined two quality improvement programs for depression, specifically a comparative analysis of treatment rates and outcomes for depressed participants with and without coexisting medical conditions. The authors hypothesized that 1) depressed patients with coexisting medical illness(es) would have worse outcomes compared to depressed patients without a coexisting illness; 2) treatment rates would not vary significantly between groups; and 3) a quality improvement program for depression would benefit both groups improving treatment rates and health-related outcomes. The sample consisted of 1,336 patients with depression randomized into one of three groups; usual care, quality improvement program with medication, or quality improvement program with therapy. The findings showed that though depressed patients with coexisting medical illness had similar rates of treatment, they had worse depression outcomes compared to patients without coexisting medical illness. However,
improving the quality of treatment did show some improvements for depressed patients with coexisting medical illness, offering evidence of the importance of making greater efforts to include the medically ill when implementing quality improvement programs for depression.

Two studies (Kurdyak & Gnam, 2004; Teh, et al., 2008) examined the effects of chronic medical conditions on the quality of depression care for persons with coexisting illness and are described below. Teh and colleagues (2008) analyzed data from the National Survey of Alcohol, Drug, and Mental Health Problems, a survey of community-based individuals, to “describe the use and quality of depression care for people with one or more chronic medical condition (CMC)” (p.529) as well as the potential relationship between CMCs and aspects of the patient-provider relationship. The sample consisted of 1,309 patients with depression. The findings indicated that patients with a CMC and depression were more likely to have their depression recognized by a health care provider compared to patients without a CMC, but the existence of a CMC did not impact depression treatment. A second finding from the study showed the patient-provider relationship potentially mediates depression recognition among patients with chronic conditions, suggesting improving the patient-provider relationship could increase the probability of having depression recognized by a health care provider. Kurdyak and Gnam (2004) compared utilization of mental health services as well as the quality of medication management delivered in health care settings between depressed patients with and without CMCs. The sample consisted of 278 individuals with the diagnosis of major depression. The data showed that depressed persons with CMCs are more likely to receive guideline-level antidepressant treatment compared to depressed persons without a competing CMC.

Katon et al. (2010) conducted a randomized controlled trial consisting of primary care patients diagnosed with diabetes, coronary heart disease, or both and concomitant depression. Patients all reported at least one measure of poor disease control including high blood pressure, high levels of low-density lipoprotein (LDL) cholesterol, and glycated hemoglobin level of ≥8.5%. The primary purpose of the RCT was to determine if medical outcomes and depressive
symptoms would improve using a care-management intervention delivered collaboratively by nurses and PCPs in a primary care setting. After baseline biomarker measures were collected, nurse practitioners initiated depression treatment, which included self-care strategies, pharmacotherapy to control depression, and motivational coaching to help patients set treatment goals and handle barriers impeding treatment. At 12-months, the intervention group had significantly greater overall improvement than their control group counterparts “with respect to glycated hemoglobin levels, LDL cholesterol, systolic blood pressure, and depression outcomes, as well as significant between-group differences on three of the four disease-control measures” (Katon, et al., 2010, p. 2616) Additionally, intervention patients were more satisfied with their care, and reported higher scores of quality of life, contributing to the evidence that training health care providers in communication strategies (i.e., motivational coaching) can potentially affect depression and disease outcomes, especially around creating dialogue around goal setting, and competing demands.

Common suggestions from the existing research include the need for further research on how best to recognize and treat depressed patients with coexisting illness. Some of the studies suggest a collaborative approach to treatment including antidepressants, behavioral therapy, and quality improvement programs being effective in this population. Though the previous studies emphasized the importance of treating complex patients with depression, it is important to reiterate that those reasons are amplified for medically-indigent populations given issues around access to care, lower social support around mental health, and daily hassles competing with self-care of medical conditions. Important to this dissertation research is to examine the hypothesis that competing demands experienced by the patient, including their competing illnesses, may not affect depression treatment (Ani, et al., 2009; Vyas & Sambamoorthi, 2011). A summary of the studies described is included below (TABLE II.2).

In conclusion, studies show the potential impact of coexisting medical illness on depression and depression treatments (both behavioral and psychotropic). Although the described
studies support the rationale and study design of the proposed analysis, they also help identify important areas this research will address. For example, the proposed study included the following suggestions made by previous research including methods and gaps to be addressed:

- Complex patients ≥ 18 years of age compared to those studies focusing on older adults (Bogner, et al., 2005; Harpole, et al., 2005; Oslin, et al., 2002).
- Medical chart reviews to compile a list of coexisting illness compared to self-report (Koike, et al., 2002; Morris, et al., 2012; Teh, et al., 2008).
- With the use of the CIRS, most medical illnesses included compared to specific illnesses identified pre-study. Additionally, the severity of those illnesses compared to a simple count (Bogner, et al., 2005; Harpole, et al., 2005; Katon, et al., 2010; Koike, et al., 2002; Kurdyak & Gnam, 2004; Morris, et al., 2012; Simon, et al., 2005; Teh, et al., 2008; Vera, et al., 2010).
- Whereas some of the mentioned studies only examined the potential effect of comorbidity on medication adherence, (Iosifescu, et al., 2003; Koike, et al., 2002; Morris, et al., 2012; Papakostas, et al., 2003; Perlis, et al., 2004), and given the potentially harmful effects of antidepressant medications, these may not be viable options for all complex patients, the proposed study is a secondary analysis evaluating a communication intervention versus a pharmacologic regimen alone.
- Attention to the patient-provider relationship and to the continuity of care as it pertains to depression improvement for complex patients.

Primarily, this study aimed to address the gaps of (1) including the medically ill (especially giving notice to the severity of their health conditions) in an intervention to improve the quality of depression care (Koike, et al., 2002), and (2) to identify illness severity (opposed to a count of illness) as a potential causal mechanism hindering depression symptom improvement (Benton, et al., 2007). Additionally, this study explored patients’ perceptions of coexisting illness and the influence on clinical encounters and communication, and on depression care in order to gain perspective on the competing demands and treatment preferences that matter to patients (Bayliss, 2012).
TABLE II.2: Summaries of the Existing Literature since 2002 on the Effect of Coexisting Illness on Depression

<table>
<thead>
<tr>
<th>Author(s) (Year)</th>
<th>Objective(s)</th>
<th>Population</th>
<th>Outcomes</th>
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<tr>
<td>Oslin, et al. (2002)</td>
<td>To examine the relationship between specific medical illnesses and the outcomes of treatment for late-life depression.</td>
<td>671 older adult patients receiving inpatient treatment for depression from one of 71 psychiatric treatment facilities in the U.S.</td>
<td>Physical disability and the total number of medical illnesses were significantly related to change in depressive symptoms. Certain somatic disorders play a role in the treatment response of late-life depression suggesting that the effect of specific illnesses on depression may be mediated by the presence of functional disability.</td>
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<tr>
<td>Koike, Unutzer, &amp; Wells (2002)</td>
<td>Compare treatment and outcomes for depressed primary care patients with and without comorbid medical conditions and assess the impact of quality improvement programs with medication and with therapy for these patients. Depression was measured using the CES-D Scale and chronic medical conditions using self-report.</td>
<td>1,356 depressed primary care patients from six managed care organizations (46 primary care clinics) from five U.S. states.</td>
<td>At 6- and 12- month follow-up, the likelihood of having a probable depressive disorder was higher but the rates of use of antidepressant medication and specialty counseling were similar, for depressed patients with comorbid medical disorders than for depressed patients without a coexisting illness. Quality improvement programs (some were an additional cost to the patient) resulted in greater use of antidepressant medications and psychotherapy and lower rates of probable depressive disorder compared to usual care.</td>
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<td>Papakostas, Petersen, Iosifescu, Roffi, Alpert, et al. (2003)</td>
<td>To test whether the presence of comorbid medical conditions can predict clinical response or depression severity at endpoint.</td>
<td>92 patients with treatment-resistant major depressive disorder starting a 6-week trial of NT.</td>
<td>The results failed to confirm the relationship between comorbid medical conditions and poor outcome in the treatment of major depressive disorder for patients with treatment-resistant depression.</td>
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<td>Iosifescu, et al. (2003)</td>
<td>Investigate the impact of medical comorbidity on the acute phase of antidepressant treatment in patients with major depressive disorder.</td>
<td>384 adult depressed (determined using the Hamilton Rating Scale) outpatients enrolled in an 8-week open treatment with fluoxetine, 20 mg/day.</td>
<td>The total burden of medical illness (using the CIRS-G instrument) and the number of organ systems affected by medical illness had a significantly negative predictive value for clinical outcome in the acute phase of treatment in major depressive disorder.</td>
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<td>Harpole, et al. (2004)</td>
<td>RCT to determine if the presence of multiple coexisting medical illnesses (average was 3.8 conditions) affects patient response to a multidisciplinary depression treatment program.</td>
<td>1,801 depressed older adults (≥ 60 years of age) from 18 primary care clinics from eight health care organizations in five U.S. states.</td>
<td>The presence of multiple coexisting medical conditions did not affect patient response to a multidisciplinary depression treatment program (a trained nurse or psychologist working directly with the patient to determine a treatment option for depression that included either antidepressants or psychotherapy).</td>
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<tr>
<td>Author(s) (Year)</td>
<td>Objective(s)</td>
<td>Population</td>
<td>Outcomes</td>
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<tr>
<td>Kurdyak, &amp; Gnam (2004)</td>
<td>To examine the difference in quality of care for depression between depressed persons with and without a chronic medical condition.</td>
<td>287 adults ages 18 to 64 with the diagnosis of major depression evaluated using the Composite International Diagnostic Interview.</td>
<td>Depressed persons with comorbid medical conditions are more likely to receive guideline-level care for depression than are depressed persons without comorbid medical illnesses. However, the association did not persist once high utilizing patients were excluded.</td>
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<tr>
<td>Perlis, Iosifescu, Alpert, Nierenberg, Rosenbaum, &amp; Fava (2004)</td>
<td>To examine the moderating effect of general medical illnesses on treatment outcome in a controlled trial with patients whose major depressive disorder failed to respond to an 8-week trial of fluoxetine (treats depression, obsessive compulsive disorder, and other mood disorders; commonly known as Prozac).</td>
<td>386 outpatients (mean age 39.9 years) who met the criteria for major depressive disorder using the Hamilton Depression Rating Scale and had coexisting illnesses as determined by the Cumulative Illness Rating Scale.</td>
<td>Using logistic regression analysis, CIRS score was not associated with likelihood of depression remission. Coexisting medical illness(es) does not appear to be associated with significantly poorer outcomes among patients whose major depressive disorder failed initially to respond to an initial trial of fluoxetine.</td>
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<tr>
<td>Simon, VonKorff, &amp; Lin (2005)</td>
<td>A longitudinal study of depressed primary care patients with and without specific co-morbid chronic medical conditions (ischemic heart disease, diabetes, chronic obstructive lung disease) to assess differences in baseline characteristics, course of depressive symptoms following initiation of antidepressant treatment, and course of functional impairment and disability.</td>
<td>204 primary care patients identified using health plan administrative data to identify those patients initiating antidepressant treatment.</td>
<td>Depression severity in patients with diabetes at baseline was not affected by comorbidities but was in patients with ischemic heart disease. All groups were not significantly different in terms of social and emotional functioning, but those patients with coexisting illnesses reported greater physical impairment. Improvement in depression during treatment was strongly associated with change in disability.</td>
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<td>Bogner, et al. (2005)</td>
<td>To describe the influence of specific medical conditions on clinical remission of major depression in a clinical trial evaluating a care management intervention among older (≥ 60 years of age) primary care patients.</td>
<td>324 older adults and were randomly assigned to either usual care or to an intervention consisting of depression care managers offering algorithm-based depression care.</td>
<td>Usual care showed mixed results of remission depending on the illness (e.g., patients with myocardial infarction reported faster remission compared to patients without; but slower for patients with chronic pulmonary disease). Intervention patients showed no significant associations between treatment and remission. Results suggest that the association of medical comorbidity and treatment outcomes for major depression for older adults may be determined by the intensity of treatment for depression.</td>
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<td>Author(s) (Year)</td>
<td>Objective(s)</td>
<td>Population</td>
<td>Outcomes</td>
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<tr>
<td>Teh, Reynolds, &amp; Cleary (2008)</td>
<td>Determine the effect of chronic medical conditions (CMCs) on the use of and quality of depression care and to understand if the patient/provider relationship mediates the relationship between CMCs and depression care quality. Severity of depression was measured by the presence of suicidal ideation and CMCs were identified by self-report.</td>
<td>1309 adults in the U.S. with Major Depressive Disorder (MDD) identified from the National Survey of Alcohol, Drug, and Mental Health Problems. 6.1% Medicaid 16.1% uninsured 60.5% had private insurance (employer or individual).</td>
<td>Depressed people with at least one comorbid CMC were more likely to have their depression recognized than those without a CMC, though were no more likely to receive adequate depression care or patient satisfaction. Additionally, aspects of the patient/provider relationship including trust, and continuity of care may help explain the increased rate of depression recognition among patients with CMCs.</td>
</tr>
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<td>Ani et al. (2009)</td>
<td>Cross-sectional study using survey data to compare guideline-concordant treatment, and follow-up care between primary care patients with chronic medical conditions and depression, and depression alone.</td>
<td>315 primary care patients recruited from 3 separate public primary care clinics with depression at baseline using the PHQ-9. Comorbidities were measured using the Charlson Comorbidity Index.</td>
<td>No significant difference in the likelihood of depression diagnosis, guideline-concordant treatment, or follow-up care in individuals with depression alone compared to those with concomitant chronic illnesses was found. Severity of depression did contribute to being diagnosed with depression. The authors concluded that physician depression care in primary care settings is not influenced by competing demands for care for other coexisting chronic illnesses.</td>
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<tr>
<td>Katon et al. (2010)</td>
<td>An RCT designed to determine whether a primary care-based, care-management intervention (self-care and pharmacotherapy) for complex patients, delivered in collaboration by nurses and primary care providers, could improve medical outcomes (i.e., diabetes, coronary heart disease, or both) and depressive symptoms. A portion of the intervention consisted of training nurses in motivational coaching to help patients set goals and solve problems around medication adherence and self-control around diabetes management.</td>
<td>214 primary care patients identified to have a diagnosis of diabetes, coronary heart disease or both according to the ICD-9 and a PHQ-9 score of ≥10 of which ~75% were White, and ~12% were unemployed or disabled.</td>
<td>Those patients in the intervention group had greater overall one-year improvement across measurements of diabetes control and depressive symptoms. Other improvements for intervention patients included higher ratings of diabetes, coronary heart disease, and depression care compared to control patients as well as overall rating of quality of life.</td>
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<tr>
<td>Author(s)</td>
<td>Year</td>
<td>Objective(s)</td>
<td>Population</td>
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<td>Vera et al. (2010)</td>
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<td>To examine if using a collaborative care model (including cognitive-behavioral therapy and antidepressant medication) would improve clinical and functional outcomes compared to usual care (care managers encouraging depressed patients to talk to their provider about their mental health) for complex primary care patients with depression in Puerto Rico (specifically to replicate other findings outside the U.S.)</td>
<td>179 adult (≥18 years of age), Spanish-speaking primary care patients with depression (PHQ-9 and the Hopkins Symptom Checklist-20) and at least one other chronic illness (e.g., diabetes, heart disease, hypertension).</td>
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<td>Vyas, &amp; Sambamoorthi (2011)</td>
<td></td>
<td>Adults with depression and at least one chronic physical condition were clustered into body systems (e.g., cardiometabolic, respiratory) to compare treatment for depression among individuals with multiple chronic illnesses to a single chronic physical condition.</td>
<td>1,376 adults with depression and at least one chronic condition; 45% had at least two conditions, 80% identified as white, and less 10% were uninsured.</td>
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<td>Morris et al. (2012)</td>
<td></td>
<td>To determine if differences exist in overall antidepressant treatment outcomes based on the number of general medical illnesses (using self-report) in terms of depression symptom severity, medication tolerability, and psychosocial functioning.</td>
<td>Adult (18-75 years of age) primary care and psychiatric patients enrolled in a RCT comparing single medication and multiple medications to treat depression.</td>
</tr>
<tr>
<td>Jordan et al. (2014)</td>
<td></td>
<td>To study the association between multiple chronic illnesses and receiving adequate depression treatment.</td>
<td>Administrative data from 43,189 Veterans Affairs patients with a new episode of depression.</td>
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</table>
Theoretical Approach

The patients sampled for this study were largely unemployed, poor, and marginalized, and suffering from resource scarcity and economic and social demands that can supersede health behavior change and treatment adherence. Consistent with the existing research on prevention and health promotion interventions for low-income populations, it is important to recognize the economic, social, and psychosocial contexts that potentially hinder health treatment and illness improvement. The uses of theoretical models when developing interventions can help illuminate the potential impacts of these tensions as well as guide the practices around recognizing and validating patients’ experiences that could improve clinical communication and improve health outcomes (e.g., depression symptoms).
Because I am interested in exploring the impacts of coexisting illnesses on depression care and also the potential factors hindering or facilitating depression symptom improvement, I have identified two theoretical models that help me frame and understand results from the analyses, including my hypotheses.

**Competing Demands**

Competing demands often hinder care and lead to suboptimal communication between patients and providers (Williams, 1998; Rost, Nutting, Smith, Coyne, & Cooper-Patrick, 2000). Poor depression recognition and treatment in primary care has been attributed to the concept of competing demands which influence how physicians and patients decide which problems to address during a given visit, or over a sequence of visits (Henke, Zaslavsky, McGuire, Ayanian, & Rubenstein, 2009; Jaen, et al., 1994; Klinkman, 1997; Nutting, et al., 2000; Rost, et al., 2000). Given most depression care is handled in primary care settings, and most if not all patients with depression will present at least one coexisting illness, it can be difficult to prioritize treatment, as well as cause disagreement between the patient and provider on which illness is most important. Within biomedicine and social medicine, one dominant conceptual model to explain suboptimal clinical encounters and outcomes is the presence of competing demands consisting of clinical (in the form of more pressing coexisting illnesses), and social (e.g., daily hassles, economic adversity) (Jaen, Stange, & Nutting, 1994; Klinkman, 1997; Williams, 1998; Nutting et.al.2000).

*Competing demands* suggests that providers and patients each have their own (often conflicting) priorities or agendas (Nutting, et al., 2000) they each want addressed during the visit(s). The structure of the Competing Demands Model for the Delivery of Psychosocial Care (Klinkman, 1997) is comprised of three domains directly influencing clinical encounters: clinician (provider), patient, and practice ecosystem (FIGURE II.2). For the purposes of this project, patient-level demands are the primary focus in identifying potential influences that inhibit behavioral health care. The patient domain focuses on elements that directly influence the clinical
encounter. For example, at the provider-level, PCPs are required to have some level of knowledge about the symptoms of depression and differentiating depression from other possible disorders and along with attitudes, time constraints, and personal knowledge can influence decision-making and quality of care (Jaen, et al., 1994; Jaen, Stange, Tumiel, & Nutting, 1997; Klinkman, 1997; Nutting, et al., 2000; Rost, et al., 2000). Patients are expected to have similar levels of competency about their illnesses, and be able to understand how their personal knowledge and beliefs can be an asset or a hindrance for symptom improvement.

Though the presence of coexisting illnesses is found to affect both domains (patient and provider), the specific dynamics are quite different. For providers, complex patients require fundamentally different approaches to care. Treating complex patients may require more time and a higher level of skills in order to recognize and treat physical ailments as well as mental health problems; both identified as competing demands for adequate care. For patients, coexisting illnesses may dictate their care agendas, conflicting with their provider’s list of priorities for the visit. Having multiple illnesses can also influence patients’ attitudes towards their health, limiting their level of self-efficacy creating a feeling of hopelessness, affecting treatment adherence and the quality of the patient-provider interaction.
Using the model of competing demands (adapted for patient-level demands), I posit that competing demands are one means through which patients with higher levels of coexisting illness severity using the Cumulative Illness Rating Scale (CIRS), along with social and economic tensions, will experience significantly less depression symptom improvement over time and be less responsive to the intervention compared to patients with lower illness severity.

The Illness Narrative

The qualitative component of this project was guided by Kleinman’s construction of chronic illness as a disease and how patients define and experience illness (Kleinman, 1988). What we know from qualitative and narrative research about chronic illness and its effects on the human condition is the individuality of each experience. The domains that make up much of a
patient’s life including their work, family life, personal autonomy, self-efficacy, and psychosocial health are influenced by the course of chronic illness, and the manifestations of that influence can adversely impact treatment regimens and the healing process. Kleinman focuses on the *illness experience* which he defines as the:

categorizing and explaining, in common-sense ways accessible to all lay persons in the social group, the forms of distress caused by those pathophysiological processes. And when we speak of illness, we must include the patient’s judgments about how best to cope with the distress and with the practical problems in daily living it creates. Illness behavior consists of initiating treatment (for example, changing diet and activities, taking over-the-counter medication or on-hand prescription drugs) and deciding when to seek care from professionals or alternative practitioners (p. 4).

Additionally, Kleinman discusses the debilitating ways illness affects a patient’s life, how a disabling illness confines, frustrates, and disappoints the patient often leading to significant loss of interest and pleasure in participating in everyday activities - a key indicator for major depressive disorder. This experience, Kleinman argues, must be legitimized during the clinical encounter through empathetic dialogue by the “biomedical specialist” (provider) in order to effectively treat illness and establish the connection necessary for chronically ill patients. By having dialogue with their patients, providers can gain a better perspective of how illness is experienced both from a contextual and social perspective, assisting them in adopting the appropriate attitudes, knowledge, and skills necessary to treat complex patients.

The collection of interviews, the tape-recorded visits, and data sources (e.g., demographic variables, medical charts) used for this dissertation provided an understanding of patient needs and barriers when it comes to their care. Findings from the qualitative interviews of patients helped to inform a more comprehensive approach to patient behavioral health care, including a better understanding of the bi-directional effects of depression and chronic illness. The qualitative phase of this dissertation, using Kleinman’s *Illness Narratives* as a framework, aimed
to collect sometimes sensitive data on the patient’s lived experience with their illnesses including depression, and to better understand their needs and barriers when it comes to their care. This supports Kleinman’s assertion that “treatment should begin with the systematic evaluation of the psychosocial crises in (a patient’s) life experience. It should include therapeutic interventions directed at each (emphasis added) of the major problems and integrated within a comprehensive clinical approach” (p. 73). By giving primary care patients the opportunity to voice their experience, I hope to gain rich descriptions from the data, and information critical to the design of future interventions for training primary care providers in mental health recognition and treatment.

**Summary of the Theoretical Frameworks**

The frameworks and theories reviewed in this chapter serve as guides for much of this dissertation, offering rationale for the aims, hypotheses, and methods purposed. For example, though competing demands has been studied mostly at the provider-level, clinical interventions need to account for patient-level demands contributing to health behaviors and outcomes. Coexisting illnesses, a construct of the patient domain of competing demands, can contribute adversely to the clinical encounter by creating a communicative disconnect between the patient and provider as a result of conflicting agendas. Kleinman’s “Illness Narrative” helps describe the importance of understanding the experiences of each patient and how those experiences influence decision-making around health and health compromising behaviors, treatment adherence and preferences, as well as how health is prioritized.
CHAPTER III

METHODS

This chapter describes the general framework for this mixed-methods study, beginning with an overview of the randomized control trial (RCT), which guided both the quantitative and qualitative components of the study. Next, the research design, study samples, data collection procedures, and analyses for both the quantitative and qualitative portions of this study are discussed. Given the complexities surrounding mental health, a mixed-methods approach was deemed most appropriate for explaining the bi-directional relationship between depression and physical illness. Though a purely quantitative design is often appropriate for social science inquiry, qualitative data offers rich and empathic descriptions potentially resulting in a better understanding about social/health phenomena (Johnson & Onwuegbuzie, 2004).

Description of the Original Randomized Controlled Trial

Both quantitative and qualitative data for this study came from a RCT funded by the National Institutes of Mental Health (Grant #s K23MH0829972 & 3K23082997-S1) conducted at Denver Health and Hospital Authority (DHHA) from May 2010 to November 2012 (Total n = 168) (Keeley & Brody, 2007). The purpose of the RCT was to test a psychosocial strategy using an adapted form of Motivational Interviewing (MI) delivered by trained primary care providers (PCPs) to improve dialogue around depression with patients, and improve depressive symptoms. The control is national standard of care treatment for depression in clinical settings which includes assessment of suicide risk, assessment of substance abuse, and discussions with patients around depression treatment options (Mitchell et al., 2003). MI is an empirically-based counseling method designed to improve medication adherence for various chronic conditions. The investigators of the RCT originally hypothesized that MI delivered by PCPs would improve depressive symptoms for patients with a new treatment episode of depression by increasing the
adherence of antidepressant medication. The trial involved two phases: **Phase 1** included brief structured interviews delivered by trained providers using MI to improve treatment adherence for depression; collection of data on the patients’ and providers’ feasibility ratings about using MI during the clinical encounter; and assessment of treatment integrity. **Phase 2** compared the MI to standard care (Guideline Based Medical Management) to determine if MI improved adherence and outcomes. Additional aims of the RCT investigated factors that potentially mediate change in depression outcomes, and “to determine what characterizes those who adhere to treatment and recover from depression” (Keeley & Brody, 2007). For this dissertation, secondary quantitative data from the RCT study pertaining to depressive symptoms improvement was analyzed at 6-, 12-, and 36-weeks after baseline. Additionally, primary data from patients’ medical history (chart reviews) for all 168 patients and patient interviews were collected and analyzed for this dissertation study only. Table III.1 summarizes the RCT (primary study) and the dissertation study.
### TABLE III.1: Description of the Primary and Dissertation Studies

<table>
<thead>
<tr>
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<th>Primary Study</th>
<th>Dissertation Study</th>
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<tr>
<td><strong>Title</strong></td>
<td>Motivational interviewing (MI) adapted to improve depression treatment in primary care</td>
<td>Depression treatment for complex patients in primary care: The role illness severity in depression symptom improvement</td>
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<tr>
<td><strong>Description/Phases</strong></td>
<td>A randomized control trial using an adapted form of MI to improve antidepressant adherence and depressive symptoms for patients with a new episode of depression funded by the National Institutes of Mental Health (NIMH). The RCT had two phases: Phase 1 included training primary care providers in MI. Phase 2 compared MI to standard care to determine if MI improved treatment adherence and depressive symptoms.</td>
<td>A secondary (quantitative aims) and primary (qualitative aims) study the potential effects coexisting illness severity has on depression symptom improvement in primary care settings. Narrative data from complex patients concerning their lived experience with depression and chronic illnesses. The dissertation had three phases: Phase 1 scored each participants coexisting illness severity using the Cumulative Illness Rating Scale (CIRS)*. Phase 2 tested if CIRS had an impact on depression symptom improvement over time. Phase 3 conducted and analyzed semi-structured interviews with purposefully selected patients to assess their lived experience with depression including symptoms, causes, competing demands, illness treatment priority and their overall attitudes about living as a complex patient and depression.</td>
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<td><strong>Patient populations</strong></td>
<td>All participants received their health care from Denver Health and were screened for depression using the Patient Health Questionnaire-9 (PHQ-9). Inclusion criteria included: 18 years or older at baseline. PHQ-9 score of ≥10. Confirmation of depression. Informed consent. Exclusion criteria included: Receiving specialty mental healthcare during the past 90 days at of recruitment. Females either pregnant or nursing. High risk for suicide. Evidence of perinatal depression, bipolar disorder, psychosis, or active substance abuse; and cognitive, language, or hearing impairment severe enough to preclude participation.</td>
<td>All participants that completed all phases of the RCT, and inclusion and exclusion criteria followed the RCT protocol. For the qualitative phases, participants were selected based on their CIRS score and availability to gain a broad sample of perspectives. Informed consent was collected for every participant.</td>
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Aims

Assessment of patient and provider ratings of feasibility and acceptability of an adapted form of MI

Compare MI to enhanced usual care for increasing treatment adherence and improving depressive symptoms for patients experiencing a new episode of depression

To explore moderators and mediators of the effect of MI on adherence and outcomes. **Does not include a comprehensive measure of comorbidity severity**

Dissertation Study

Explored the potential effect coexisting illness severity has depression over time;

Identified how patients perceive the “bidirectional” relationship between depression and chronic illness

Identify the competing demands that influence patients’ beliefs, attitudes, and treatment preferences in receiving care for depression and physical illnesses

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**Study Setting**

The study population for the RCT consisted of patients receiving their care from Denver Health and Hospital Authority (DHHA), a comprehensive health care network that cares for about one-quarter of Denver residents *(Denver Health: About Us, 2012)*. DHHA is a network of eight family health centers, two hospital-based urgent care centers, and 15 school-based health centers. Participants were recruited from seven of the eight family health centers and from the main hospital. The adult patient population that utilized services is approximately, 16% non-Hispanic Black, 57% Hispanic, 19% non-Hispanic White, and 8% other, with 10% being 65 years or older. Many of the patients at DHHA have incomes that fall below the federal poverty line and most are enrolled in either Medicaid or the Colorado Indigent Care Program (CICP). Given that DHHA provides health care regardless of ability to pay, services are restricted to priority care and mental and/or behavioral health problems are often under-diagnosed and untreated. The RCT recruited patients from seven DHHA clinics located around the Denver Metro area.

**Study Participants**

The RCT enrolled participants from DHHA. All participants were required to be at least 18 years of age and have had contact with a primary care provider within 12-months prior to the study. Additionally, they had to have been diagnosed with moderate to severe depression at
baseline. Those patients with serious alcohol or drug addictions, no access to a telephone, or without some proficiency in English were excluded from the RCT. All participants gave their informed consent. Women and men 18 years of age or older who were receiving care at Denver Health and had received a diagnosis of moderate to severe depression were included in the study. Patients were excluded from the study for the following reasons:

- Receipt of an antidepressant medication in the previous 90 days other than a low-dose tricyclic antidepressant for pain or Trazodone for sleep
- Receiving interpersonal or cognitive behavioral psychotherapy focusing on depression
- Pregnant or nursing
- Drug or alcohol dependency or abuse (excluding caffeine or nicotine)
- High risk for suicide
- Inability to communicate in English
- Lifetime bipolar disease
- Psychosis
- History of autism, mental retardation, or pervasive developmental disorders
- Cognitive, language, or hearing impairment severe enough to preclude participation.

Measures

Patient Health Questionnaire-2 and -9. The Patient Health Questionnaire-2 (PHQ-2) (Appendix B) was used as one part of the screening process and to assess baseline depressive symptoms. The PHQ-2 is a 2-item measure that inquires about the frequency of depressed mood and anhedonia, defined as loss of interest in previously interesting or enjoyable activities (Kroenke, Spitzer, & Williams, 2003). The stem question of the PHQ-2 is

Over the last 2 weeks, how often have you been bothered by any of the following problems?

The 2 items are:

Little interest or pleasure in doing things (i.e., anhedonia) and

Feeling down, depressed, or hopeless.
The Patient Health Questionnaire -9 (PHQ-9) (Appendix C) is a 9-item scale that includes the two items that make up the PHQ-2 along with the following additional items:

- Trouble falling or staying asleep, or sleeping too much
- Feeling tired or having little energy
- Poor appetite or overeating
- Feeling bad about yourself or feeling that you are a failure or have let yourself or your family down
- Trouble concentrating on things such as watching television or reading
- Moving or speaking so slowly that other people have noticed
- Thoughts that you would be better off dead (Suicidality)

As measures, the PHQ-2 score can range from 0-6, and the PHQ-9 can range from 0-27, each item scored as follows:

- 0 = “not at all”
- 1 = “several days”
- 2 = “more than half the days”
- 3 = “nearly every day”

The PHQ-9 can be a useful tool for diagnosing and helping patients to manage their depression in primary care settings, mainly because it both offers a continuous measure of depressive symptoms and a method to monitor change and treatment outcomes (Arroll, et al., 2010). In a report of the largest validation study of the PHQ-2 and -9 in a primary care setting, Arroll and colleagues concluded the PHQ-2 was very sensitive (0.86) and had a specificity of 0.78 for a diagnosis of depression when compared to the Composite International Diagnostic Interview (CIDI) (2010). The PHQ-9 had similar sensitivity (0.74), but a higher specificity (0.91) with a cutoff score of ≥10 (Arroll, et al., 2010), which was the cutoff score used for this study. A 2004 study of the reliability and validity of the PHQ-9 compared to the Hopkins Symptom Checklist Depression Scale (SCL-20) reported a high rating for test-retest reliability (0.81 for worst-case sample and 0.96 for best-case sample), and a significantly greater responsiveness at 3 months; -1.3 (95% confidence interval [CI]) versus -0.9 (Lowe, Unutzer, Callahan, Perkins, &
Kroenke, 2004). Two other studies (Lowe, Grafe, et al., 2004; Lowe, Spitzer, et al., 2004) have shown the PHQ-9 having “superior criterion validity as a diagnostic measure” (Lowe, Unutzer, et al., 2004, p. 1195) compared to other self-report measures for depression.

Description of the Dissertation Study

As previously mentioned, the primary quantitative data from this study came from the two-year prospective RCT (discussed above), as well as the patients selected for the qualitative phase. The quantitative portion of the study reported here is a secondary analysis of the RCT data (n=168). The primary goal of the quantitative component of this study was to determine the potential influence coexisting illness(s) and their severity have on depression symptom improvement over time.

Measures

Cumulative Illness Rating Scale. For this study, the Cumulative Illness Rating Scale (CIRS) (Linn, Linn, & Gurel, 1968) (APPENDIX E) was added as a primary data collection source to evaluate the severity of each participant’s coexisting illnesses, in addition to their depression. Data derived from the CIRS are useful for quantifying and summarizing medical illness burden. (Kemp, et al., 2010). Using medical record review and International Statistical Classification of Diseases and Related Health Problems (ICD)-10 diagnostic and procedure code data, physical and behavioral morbidities were identified at baseline. The comorbid diseases of the patient was rated using the CIRS, which classifies comorbidities by 14 organ systems affected and rates them according to their severity from 0 to 4 (Linn, et al., 1968). The scores are as follows:

- 0 = “no problem”
- 1 = “current mild or past significant problem”
- 2 = “moderate disability requiring first-line treatment”
- 3 = “uncontrollable chronic problems or significant disability”
- 4 = “end-organ failure requiring immediate treatment” (for this study, no 4s was scored because presence of severe illnesses are including in the exclusion criteria)
Existing literature supports the use of the CIRS calculated from chart reviews along with high recommendations as an available method of measuring comorbidity (de Groot, et al., 2003). CIRS scores were only collected once, at baseline, because it was not the aim of this project to evaluate improvement in any illnesses other than depression as measured by the PHQ-9.

In accordance with existing literature CIRS scores was stratified into three categories based from each patient’s total score:

- Low (0-7)
- Moderate (8-14)
- High (15+)

It was assumed that because patients were seeing their primary care provider for a separate reason when recruited for the RCT, they will have at least one coexisting illness in addition to their depression. Then, CIRS scores were categorized into three ratings for each patient:

- Total Score.
- Number of categories endorsed.
- Severity index (total score/number of categories endorsed)

Levels of severity rating for each of the 14 systems of the CIRS were measured using a 0-4 scoring system. Every single disease listed in the patient’s medical chart was classified into the appropriate system and then given a score using the specific guidelines for each disease/system (Hudon, Fortin, & Soubhi, 2007). For reference, the general rules for each potential score are listed below (Hudon, et al., 2007):

0- No problem affecting that particular system (no disease listed)
1- Current mild problem.
2- Moderate disability or morbidity and/or requires first line therapy.
3- Severe problem and/or constant and significant disability and/or hard to control chronic problems.

Extremely severe problem and/or immediate treatment required and/or organ failure and/or severe functional impairment.
Sociodemographic information was used as explanatory variables and included age, household income, race/ethnicity, gender, and employment status all which were collected at baseline and self-reported. The demographic variables were included as covariates in the statistical models. Additionally, they were used to assist with the stratified purposeful sampling for the qualitative interviews.

**Data Collection Procedure**

The RCT study first randomized PCPs into MI-training (treatment) or enhanced usual care (control) and the patients were contacted for participation in the study. The RCT and the amendments necessary for the secondary analysis and qualitative interviews were approved by the Colorado Multiple Institutional Review Board (Protocol# 08-1282). The research team contacted primary care patients who met the inclusion criteria first by telephone to discuss the study, consent to the study, and to make an appointment in accordance with a future visit to meet in order to complete the screening questionnaires. At their clinic visit, all participants were again asked to consent to the study. If consented, patients completed a demographic survey (APPENDIX D), as well as the Patient Health Questionnaire (PHQ-9) (APPENDIX C), a more thorough instrument for measuring major depression compared to the PHQ-2. The demographic data collected included employment status, marital status, income and housing status (e.g., rent, own), level of education completed, and race/ethnicity. The PHQ-9 was used to ascertain major and minor depression at baseline and follow-up. PHQ-9 scores were collected at four time points, baseline, 6-, 12-, and 36-weeks. In practice, the testing dates for each patient varied and not every patient was screened at each time point.

The CIRS were scored using medical and pharmaceutical records by a licensed Physician’s Assistant (PA) employed at Denver Health (in accordance with the suggested credentials necessary to score the CIRS appropriately). A physician also scored 25 patients chosen randomly in order to compare scores with the PA to ensure fidelity along with allowing for dialogue around scoring procedures and consistency.
The independent variables selected for the quantitative analyses were determined by the literature reviewed in Chapter 2, as well as the existing RCT dataset that was collected. Since identifying competing demands of primary care patients was an aim for this analysis, independent variables were selected based on factors that potentially influence depression care, particularly for complex patients.

Data Analysis

The purpose of this dissertation study was to test whether severity of coexisting medical illnesses is related to depression symptom improvement over time for depressed complex primary care patients. Both within-person changes in depression (i.e., intraindividual change) and between-person changes in depression (interindividual differences) were analyzed using hierarchical linear modeling (HLM). By using HLM, the potential differential impacts of illness severity on depression trajectory over time were tested. Applying HLM to longitudinal data offers the opportunity to explore theoretically different questions, which is not possible with regression analyses or cross-sectional data (Taylor, Ntourmanis, Standage, & Spray, 2010).

To address the Aim 1, quantitative data were analyzed using Hierarchical Linear Modeling (HLM). HLM was selected because of its fit for studying the predictors of individual change as well as analyzing hierarchically structured data accounting for the nested structure of these relationships including the individual, ecological-contextual, and individual-contextual relationships often neglected in logistic and regression models (Raudenbush & Bryk, 2002; Subrahmanian, Jones, & Duncan, 2003). Given the data collected for this study were collected at various time points, HLM allowed nesting repeated scores within persons as an individual (Level 1) measurement in order to show individual differences in growth curves (Kreft & De Leeuw, 1998; Tabachnick & Fidell, 2007). By organizing the data into hierarchies (e.g., repeated measures of depression nested within patients), HLM allowed for individual-level variables, as well as group-level variables to be included in the analyses (Kreft & De Leeuw, 1998). Additionally, because not every patient was screened at every time point, HLM was optimal
method of analysis of change (e.g., repeated measures ANOVA) because it did not require an
equal number of responses from each patient, meaning every patient could be included in the
analysis even with missing values (Raudenbush & Bryk, 2002; Taylor, et al., 2010).

Each time measurement of depression was nested within each patient. Equation 1
outlines the basic rudiments of the within-patient (i.e., Level 1) models used in the linear growth
models:

\[ Y_{tij} = \pi_{0ij} + \pi_{1i}(TIME POINT)_{ti} + e_{ti} \]  

(1)

where:

\[ Y_{tij} \] is the outcome at time \( t \) for patient \( i \);

\((TIME POINT)_{tij}\) takes on a value of 0 at baseline, a value of 6 at 6-weeks, a value of 12
at 12-weeks, and a value of 36 at 36-weeks;

\( \pi_{0ij} \) is the initial status of patient \( j \), that is, the expected outcome for that patient at
baseline (when \( t = 0 \));

\( \pi_{1ij} \) is the depression score change rate for patient \( j \) during the study;

and \( e \) is the error term.

The estimate parameter from the within-patient model (Level 1) will then be used as the outcome
variable in the between-patient equations (Level 2):

\[ \pi_{0ij} = \beta_{00} + \beta_{01}(\text{comorbidity severity})_{1} + \beta_{02}X_{2} + \beta_{03}X_{3} + e_{0t} \]  

(2)

\[ \pi_{1ij} = \beta_{10} + r_{1i} \]  

(2a)

where:

\( \beta \) is the regression parameter;

\( X \) is a time-invariant predictor variable (e.g., patient’s level of comorbidity severity, and
gender);

and \( e \) is the error term.

Degree of variance in the study variables was explored using intercept-only models (i.e.,
no predictor variables were included) for all study variables, separated into two parts: variance associated with Level-1 errors (within-patient), and Level-2 errors (between-patient). From these models, interclass correlations coefficients (ICCs) were computed to describe the proportion of variance associated with the between-patient level. Additionally, statistical assumptions associated with multilevel modeling were assessed (e.g., error terms are normally distributed, homoscedasticity, and independence of observations) (Raudenbush & Bryk, 2002). In addition to the HLM, a Repeated Measures ANOVA was used to test the correlations between the main variables (i.e. PHQ-9 and CIRS).

**Qualitative Primary Data Research Design**

In general, the qualitative aim of this dissertation was to triangulate the quantitative findings particularly around complex primary care patients’ experience with depression as a coexisting illness, as well as the competing demands expressed by patients including illnesses, issues with employment and income, and other identified daily hassles. An additional intent of the interviews was to inform future depression interventions about how patients regard their depression in terms of treatment preferences and communication with their provider during the clinical encounter, primarily among socially and economically disadvantaged adults with minimal access to psychiatric services. Although the aims of the study are supported by the literature, the paucity of contextual knowledge about bi-directional relationship between depression and physical illness and their treatments from the patients’ perspective justified use of qualitative research strategies, which can garner information often not obtainable with quantitative research methodologies (Addison, 1999; Pope & Mays, 1995).

**Data Collection Procedure**

Though the first draft of the interview guide (Appendix F) was developed prior to the first interview, the guide was amended as necessary to best elicit the information to address the aims, which is often advisable in qualitative research (King & Horrocks, 2010). The interview
guide was developed using an iterative process that included the author of this dissertation, three of the dissertation committee members (KL, DM, & RK) as well as the data manager of the original RCT. Four “pilot” interviews were completed followed by a modification of the question guide that included changing particular words, order of the questions, and the number of questions. Two more interviews were completed before the final question guide was completed. A copy of the final interview guide is included as Appendix F. Interviews were only conducted in English.

Using purposeful sampling techniques, patients were stratified by CIRS score (i.e., low, moderate, high). Nineteen patients were interviewed to collect descriptive accounts about patients’ attitudes about depression and depression treatment. Six of the interviews were conducted by the author of this dissertation and the remaining 13 by the data manager of the original RCT. Interviews were done by telephone and lasted approximately 10-20 minutes each. The telephonic method was selected given that the patients could not be directly observed, and the patient population at DHHA suffers disproportionately from challenges around transportation (e.g., some patients have identified that they take several bus routes to get to their primary care center) and childcare. The patients interviewed were compensated for their participation with $25.00 gift cards for a local supermarket.

The interviews were audiotaped and fully transcribed for analysis. The semi-structured format was selected to enable the opportunity for patients to elaborate about their experiences and for the interviews to be less restrictive, while still maintaining a level of fidelity through the use of a question guide to provide consistency in the question asked during each interview.

Patton (2001) identified six types of interview questions, each looking to elicit certain information from the participant. The interview guides for this study will focus on three of the categories:
• **Experience/behavior questions:** These questions focused on specific actions and reactions experienced by the patient that could be observed such as reactions to a physical or psychological diagnosis; reactions to questions asked by the PCP about depression and other psychological distress; and how (if at all) the patient initiates dialogue with their provider about their concerns.

• **Opinion/values questions:** These questions focused on what the patient thinks about the topic of interest (e.g., depression and physical illness) and/or how their thoughts about the topic relate to their values, goals, and intentions. For example, the interview script will include questions about what the patient thinks is the best way to treat depression and his/her physical illnesses; how the patient sees the relationship between his/her psychological and physical health; and what the patient’s intentions during a primary care visit given his/her current health status.

• **Feeling questions:** These questions focused on the emotional experiences felt by the patients. It is important to phrase these questions with the term *emotion* in the question not only to elicit the patient’s feelings but also to differentiate them from *opinion/values* questions, which Patton warns can happen without intention. Examples include ‘what feelings does your health status provoke in you?’

**Data Analysis**

Data collected from the interviews (text transcribed from audio recordings) were interpreted using a blending of suggested techniques for systematically examining qualitative findings. Consistent with the “immersion” and “crystallization” techniques as identified by Crabtree and Miller (1999), the initial techniques consisted of multiple, in-depth readings of the transcripts (immersion), with a different focus for each reading depending on assumptions and observations made during initial readings (crystallization). Other reflective techniques consisted of dialogue with colleagues and advisors about patterns and emerging themes and to cross-check interpretations and codes derived from the interviews (Addison, 1999; Creswell, 2009). Members of the dissertation committee met on several occasions to discuss the themes identified from the interviews as well as to check for compliance with the research questions posed for this dissertation research. The analysis was concerned with both the language and the content of what
the patients shared during the interviews to understand their lived experience dealing with illness from their perspective (King & Horrocks, 2010).

For this study, a variation of the three-stage thematic analysis system (FIGURE III.1) was adapted to code the transcribed interviews (King & Horrocks, 2010). Though the process has a sequential order, changing and rethinking codes occurred and stages repeated to best interpret the data. The first stage identified sections of the interviews that were relevant to the study aims. Initial coding consisted of relatively broad a priori codes developed from the existing literature and the qualitative aims of the study while highlighting any quotes that are relevant to aims with comments that will help organize the text into themes. The second stage organized the broad coding and the highlighted sections into descriptive codes, using single words or short phrases relevant to the study aims. The descriptive codes were applied to all of the interviews and elicited the strength of the concepts in the data and tied together any similarities across the interviews. The third and final stage of coding entailed identifying key themes in the text by grouping together descriptive codes and any emerging themes that shared common meanings, along with creating a diagram that exhibited the relationships within the text (APPENDIX E). The initial results from the qualitative analysis were reported by theme then organized by more specific themes, and finally linked and corroborated using Dey’s Qualtitative Analysis as an Iterative Process model (1993) (FIGURE III.1). The “stages” of this model emphasized a spiral design for qualitative research analysis, less sequential and linear, with the data “looping back and forth through various phases within the broader progress of the analysis” (Dey, 1993).
Qualitative Validity

In order to improve the validity of the qualitative findings, a clear explanation of the data collection methods and analysis was included as part of this study along with the demographic and health data of each participant (patient) to show differences among the interviewees which can be conducive to obtaining different perspectives (Mays & Pope, 2000). Additionally, academic advisors and colleagues reviewed the findings to refine key themes and codes. In order to ensure accuracy and credibility of the qualitative results, I employed procedures including (Creswell, 2009):

- Checking transcripts for mistakes made during transcription of the interviews.
- Staying consistent with using codes derived from the literature and the interviews, and documenting any changes to the code book.
- Sharing the analysis with committee members familiar with the study.
- Utilizing an external auditor with qualitative analysis experience but with little to no knowledge of the study.
Quality Checks at all Stages of the Analysis

Stage one: General Coding
Read through entire transcript
Remove any text that could reveal the identity of the patient
Define and identify a priori codes
Highlight relevant material and attach notes and comments
Repeat for each transcript

Stage two: Descriptive/Interpretive Coding
Define descriptive codes
Cluster descriptive codes
Interpret the meaning of the clusters in relation to the research questions
Apply interpretive codes to full data set

Stage three: Overarching Themes
Identify key themes for the data set as a whole (comparison analysis)
Construct a diagram to represent relationships between levels of coding in the analysis
Include quantitative findings for the final analysis

FIGURE III.1: Description of the Qualitative Analysis
CHAPTER IV

RESULTS: QUANTITATIVE ANALYSIS

This chapter reports the quantitative results for the secondary analyses of the original RCT dataset, including descriptive statistics of the variables, correlations, and hierarchical linear regression analyses. Descriptive statistics and correlations were run using SPSS, Version 22.0 (IBM Corp, 2013), while all hierarchical analyses were run using the student version of HLM, Version 7 (Scientific Software International, 2013).

Quantitative Patient Population

Table IV.1 summarizes the sociodemographic characteristics of the sample. All 168 patients from the original RCT were eligible for this secondary analysis. Patient characteristics including age, gender, income, and employment status are summarized in Table IV.1. Of the 168 patients, the mean age of the sample was 48.9 years of age (SD=12.3) and 118 (70.2%) were female. Non-white and Hispanics and African Americans represented the largest racial/ethnic groups and over half of the patients (50.3%) reported an income of less than $10,000 in the past year at baseline; over half of the sample also reported being unemployed (53.4%), and were either looking for employment or unable to work due to physical or mental illness(es). As shown by the demographics, a majority of the sample is low-income, unemployed (many due to mental or physical disability), and racial/ethnic minorities, all groups disproportionately affected by untreated mental illness and concomitant illnesses.
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total (n=168)</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>48.1 (13.2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>118 (70.2)</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>86 (51.3)</td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>12 (7.1)</td>
<td></td>
</tr>
<tr>
<td>Some College</td>
<td>14 (8.3)</td>
<td></td>
</tr>
<tr>
<td>Vocation/Trade</td>
<td>40 (23.8)</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>57 (33.9)</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>57 (33.9)</td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic white</td>
<td>39 (23.2)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>15 (9.0)</td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; $10,000</td>
<td>82 (54.7)</td>
<td></td>
</tr>
<tr>
<td>&lt; $15,000</td>
<td>29 (19.3)</td>
<td></td>
</tr>
<tr>
<td>&lt; $25,000</td>
<td>25 (16.7)</td>
<td></td>
</tr>
<tr>
<td>&lt; $35,000</td>
<td>8 (5.3)</td>
<td></td>
</tr>
<tr>
<td>&gt; $35,000</td>
<td>6 (4.0)</td>
<td></td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working for wages</td>
<td>40 (23.8)</td>
<td></td>
</tr>
<tr>
<td>Unemployed (undisclosed reason)</td>
<td>26 (15.5)</td>
<td></td>
</tr>
<tr>
<td>Unemployed (due to mental or physical illness)</td>
<td>62 (36.9)</td>
<td></td>
</tr>
<tr>
<td>Student/homemaker/other</td>
<td>40 (23.8)</td>
<td></td>
</tr>
</tbody>
</table>
Research Question 1

Research question 1 (RQ1) aimed to determine if the severity of coexisting medical illnesses impacts depression symptom improvement over time for primary care patients experiencing a new episode of depression over time. It was hypothesized that patients with high competing illness severity would experience significantly less depression symptom improvement over time and would be less responsive to the RCT than those with lower illness severity.

Depression and Illness Severity

The Patient Health Questionnaire (PHQ-9) for all 168 patients were collected and were the main outcome of interest for the original RCT and used to measure depression change over time for this study. The range for the PHQ-9 is 0-27, with data collected at four time points: baseline, 6-, 12-, and 36-weeks. From baseline to 36-weeks, the mean PHQ-9 went from 15.99 to 11.15 for the entire sample (TABLE IV.2).

<table>
<thead>
<tr>
<th>Time point</th>
<th>Mean (SD)</th>
<th>Standard Deviation</th>
<th>95% Confidence Interval of the Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
<td>16.0 (4.2)</td>
<td>4.2</td>
<td>15.4 - 16.6</td>
</tr>
<tr>
<td>6 weeks</td>
<td>11.5 (5.3)</td>
<td>5.3</td>
<td>10.6 - 12.4</td>
</tr>
<tr>
<td>12 weeks</td>
<td>11.8 (5.6)</td>
<td>5.6</td>
<td>10.9 - 12.8</td>
</tr>
<tr>
<td>36 weeks</td>
<td>11.2 (5.6)</td>
<td>5.6</td>
<td>10.2 - 12.2</td>
</tr>
</tbody>
</table>

Given that RQ1 is designed to test the potential impact of illness severity, some of the data collected to measure illness severity are reported below: the mean scores for illness severity, as well as data concerning the body systems affected by illness (e.g., psychiatric, vascular). For the quantitative analysis, CIRS are reported using two separate categories:
- Total systems affected (14 possible systems)
- Total CIRS score (0-54)

Total CIRS scores were first measured by the total sample (n=168) and stratified into one of three categories, low, moderate, or high. Among the patients in the RCT, CIRS scores were fairly evenly distributed. All but one patient had at least a CIRS score of 1. Of the 168 patients, 35.7% reported a CIRS scored between 0 and 7 (low), 33.3% scored between 8 and 12 (moderate), and 31% scored between 13 and 56 (high) (FIGURE IV.1). Since the distribution was fairly evenly distributed, additional analyses are reported here to look for differences among the sample including age, gender, and level of impairment.

![Bar Chart](FIGURE IV.1: Total CIRS (0-56) Score Reported By Percent of the Sample)

Table IV.3 reveals that there is a statistically significant relationship between age an total CIRS score, such that as age increases so does the burden of coexisting illness severity.
### TABLE IV.3: Total CIRS by Age (n=168)

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Age 18-39</th>
<th>Age 40-59</th>
<th>Age ≥ 60</th>
<th>$\chi^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Low (0-7)</td>
<td>52</td>
<td>31.0</td>
<td>28</td>
<td>59.6</td>
<td>21</td>
</tr>
<tr>
<td>Moderate (8-12)</td>
<td>56</td>
<td>33.3</td>
<td>15</td>
<td>31.9</td>
<td>30</td>
</tr>
<tr>
<td>High (13-56)</td>
<td>60</td>
<td>35.7</td>
<td>4</td>
<td>8.5</td>
<td>39</td>
</tr>
</tbody>
</table>

***p < 0.001, Test: Chi-Square (Likelihood ratio statistic)

Figure IV.2 presents the means and standard deviations of the PHQ-9 scores (depression scale) at all four time points stratified by the three levels of total CIRS scores (low, moderate, high). As can be seen, depression scores for all three groups improved at 36 weeks. Those patients in the moderate CIRS range (8-12) saw the most improvement over time.
Mean PHQ-9 at baseline was 16.0 and 11.2 at 36-weeks with a mean change of 3.47, while the mean CIRS score was 10.8. The correlation between change in PHQ-9 at 36-weeks and CIRS score was -0.4 (TABLE IV.4).

**TABLE IV.4: Main Variable Correlations**

<table>
<thead>
<tr>
<th></th>
<th>Mean (SD)</th>
<th>Pearson Correlation (PHQ-9 Change Over 36-weeks)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHQ-9 Change Over 36-weeks</td>
<td>3.5 (5.5)</td>
<td>-</td>
</tr>
<tr>
<td>CIRS Total</td>
<td>10.8 (5.3)</td>
<td>-0.4</td>
</tr>
</tbody>
</table>

Table IV.5 reports the results from the linear regression looking at change in depression score over 36-weeks and total CIRS. Less than 1% of the variance is accounted for change in
depression is accounted by total CIRS score at baseline (-0.04). This does not support the hypothesis of the expected strong affect CIRS would have on change in depression.

**TABLE IV.5: Results of Regressing Change in Depression on Illness Severity (n=125)**

<table>
<thead>
<tr>
<th>Step</th>
<th>β</th>
<th>Adj. $R^2$</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Total CIRS Score at Baseline</td>
<td>-0.04</td>
<td>-0.04</td>
<td>0.29</td>
</tr>
</tbody>
</table>

**Results from the Hierarchical Linear Modeling**

The first HLM model that was tested was the baseline model with no predictors. The interclass correlation (ICC), which describes the percent of variance in depression scores between patients, was 0.69. ICC is the proportion of the between-individual variance to the sum of the between- and within-individual variances of an outcome variable and generally ranges between 0 and 1. Hox (2002) interpreted ICC as “the proportion of the variance explained by the grouping structure in the population” (p.15). ICC can also be (roughly) viewed as the average relation between any pair of observations (i.e., the PHQ-9 scores) within a cluster (i.e., a patient). With this model, the intercept, $\pi_0$, and time, $\pi_1$, were examined for reliability (TABLE IV.6). The reliability estimates represent the proportion of the variance in the Level-1 estimates that is parameter variance. The reliability of the random effect of the level 1 intercept is the average reliability of the level 2 units. It measures the overall reliability of the OLS estimates for each of the intercepts.

The reliability estimates are .42 for intercept and .05 for slope. These indicate that the slope (change in depression) is not a reliable estimate. In other words, PHQ-9 score is not a reliable measure of a patient’s depression change time (TABLE IV.6).
TABLE IV.6: Results from the Random Coefficient Estimates

<table>
<thead>
<tr>
<th>Random level-1 coefficient</th>
<th>Reliability estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept, $\pi_0$</td>
<td>0.420</td>
</tr>
<tr>
<td>TIME Slope, $\pi_1$</td>
<td>0.054</td>
</tr>
</tbody>
</table>

For the Level-1 model (Table IV.7), each time measurement of depression was nested within each patient. Equation 1 outlines the basic rudiments of the within-patient (i.e., Level 1) models used in the linear growth models:

\[ Y_{tij} = \pi_{0ij} + \pi_{1ij}(TIME\ POINT)_{tij} + e_{tij} \]

[EQUATION 1]

Table V.10 shows the results from a random coefficient model. The fixed results indicate that the average PSQ-9 score at baseline was 14.1 and that the average change in slope across patients over the four time points (BL, 6-weeks, 12-weeks, 36-weeks) was -0.1 (which indicates a statistically significant decrease in depression over time). It can be inferred from the random effects results that the relationship between CIRS and change in depression over time does not vary significantly across the patient population; that there are no differences between patients in terms of change in depression over time slopes. This was expected given that the model did not have reliable estimates (TABLE IV.7).
TABLE IV.7: Results from Depression Over Time Model

<table>
<thead>
<tr>
<th></th>
<th>Coeff (SE)</th>
<th>Fixed Effects</th>
<th>p</th>
<th>Random Effects</th>
<th>Random Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>t</td>
<td>p</td>
<td>Variance</td>
<td>χ²</td>
</tr>
<tr>
<td>Mixed Model</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept, π₀</td>
<td>14.13</td>
<td>43.34</td>
<td>&lt;0.001</td>
<td>7.88</td>
<td>260.20</td>
</tr>
<tr>
<td>Intercept, β₀₀</td>
<td>(0.33)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TIME Slope, π₁</td>
<td>-0.10</td>
<td>-7.00</td>
<td>&lt;0.001</td>
<td>0.001</td>
<td>159.94</td>
</tr>
<tr>
<td>Intercept, β₁₀</td>
<td>(0.01)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deviance</td>
<td>3398.49</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Significant if p < 0.05

Given that the Level-1 showed no difference between patients in terms of depression symptom improvement over time, theoretically, a Level-2 HLM model is unnecessary because it is not expected to yield any difference from the Level-1 results. The Level-2 model was completed for illustrative purposes (TABLE IV.8).

The estimate parameter from the within-patient model (Level 1) was used as the outcome variable in the between-patient equation:

\[
π_{0ij} = β_{00j} + β_{01j}(\text{comorbidity severity})_{1j} + β_{02j}X_{2j} + β_{03j}X_{3j} + e_{0ij}
\]

[EQUATION 2]
As expected, the CIRS was not a statistically significant predictor of change in depression over time, which was the first research question.

**Response to Research Question 1**

Given the reliability of the estimates offer little variability (TABLE IV.6), it is unnecessary to expand the between-subjects model in order to examine the possible factors associated with depression symptom improvement and chronic illness severity. If most of the variability is due to error, there would likely be no systematic relations between the estimates and the second model estimates. It could then be falsely concluded that there are no relationships when in fact the data are incapable of detecting such relationships. For the individual growth parameter reliability coefficients, averaging the estimates across the n individuals provides a summary index of the instrument's reliability in measuring each of the growth parameters on this population of subjects. The estimated variance components for the PHQ-9 reliabilities were low, especially for the variation in the growth rate parameters for the depression assessment over time, meaning the depression levels for individual patients changed at a relatively constant rate across individuals.
CHAPTER V

RESULTS: QUALITATIVE ANALYSIS

Cause my illnesses keep me down. Depression keeps me down. So it is just a different form to me. It is just another added on disease, so to speak.

Yeah. I mean you know, pain. Like if I have aches and pains more, it (depression) hurts more. If I'm you know, if I'm sick with a cold or something, things feel like harder. I don't know…it just...everything is harder. Let's just say everything is bigger and harder.

This chapter reports the qualitative results from semi-structured interviews conducted with a sample of participants from the original RCT. The chapter includes identified themes, sample quotes, as well as simple counts of all the codes from every interview. All handling of the data was done using ATLAS.ti™ Version 7.0, a software package designed to organize qualitative data, as well as assist the process of assigning and managing codes assigned to the text.

The primary aim of the qualitative results was not to only offer context to the quantitative results, but to increase the overall strength of the study, and to derive data to compare with the quantitative results as well as to maximize any similarities and the differences of information (Creswell, 2009). The qualitative data was used to answer two of the three study research questions:

- How do complex patients describe the lived experience with depression and concurrent illnesses?
- How does a diagnosis of a new episode of depression change the management and prioritization of concurrent illness for complex patients?
Qualitative Patient Population

The sample for the qualitative analysis included 19 participants using Denver Health for their primary care with 4 being male; CIRS ranging from 6-21, ages ranging from 36-68; and baseline PHQ-9 scores ranging from 10-25, which is representative for the larger quantitative sample (TABLE V.1).
TABLE V.1: Interview Participant Characteristics

<table>
<thead>
<tr>
<th>Interview ID</th>
<th>Gender</th>
<th>Age</th>
<th>BMI</th>
<th>PHQ-9 Baseline (0-27)</th>
<th>CIRS (0-56)</th>
</tr>
</thead>
<tbody>
<tr>
<td>101</td>
<td>F</td>
<td>54</td>
<td>45</td>
<td>14</td>
<td>8</td>
</tr>
<tr>
<td>102</td>
<td>F</td>
<td>52</td>
<td>43</td>
<td>16</td>
<td>21</td>
</tr>
<tr>
<td>103</td>
<td>F</td>
<td>36</td>
<td>46</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td>104</td>
<td>M</td>
<td>68</td>
<td>22.9</td>
<td>10</td>
<td>7</td>
</tr>
<tr>
<td>105</td>
<td>F</td>
<td>46</td>
<td>45.4</td>
<td>20</td>
<td>13</td>
</tr>
<tr>
<td>106</td>
<td>F</td>
<td>56</td>
<td>33.4</td>
<td>17</td>
<td>12</td>
</tr>
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<td>107</td>
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The remainder of this chapter describes the major themes interpreted and analyzed from the interview data. The qualitative research questions and specific aims are weaved within the sections along with emergent themes that help to describe the narrative offered by participants with depressive symptoms. The analysis resulted in eight themes and 23 categories (TABLE VI.2) describing the participants’ experiences with a new episode of depression and as a complex
Research Question 2

In order to assess participants’ lived experience with depression and concurrent illnesses, participants were asked a range of questions to elicit their narrative. Questions were focused on how participants understand, experience, and negotiate depression, along with their perceptions of the relationship between their mental and physical symptoms and their health. For the purposes of this study, Kleinmann’s definition of the illness experience aided the development of this section of the question guide, as well as the analyses:

Illness is the lived experience of monitoring bodily processes such as respiratory wheezes, abdominal cramps, stuffed sinuses, or painful joints. Illness involves the appraisal of those processes as expectable, serious, or requiring treatment. The illness experience includes…the forms of distress caused by those pathophysiological processes. And when we speak of illness, we must include the patient’s judgments about how best to cope with distress and with the practical problems in daily living it creates (emphasis added). (p.4)(Kleinman, 1988)

Themes emerged from across the data providing insight on how depression is viewed, felt (symptoms), and if it has any impact on physical health and overall quality of life.

Perceived Causes of Depression

Given the characteristics of the study population, a priori themes were hypothesized when analyzing the perceived causes of depressive symptoms. For example, all 168 patients sampled for the original RCT had at least one other concomitant illness, therefore it was hypothesized that coexisting illnesses could be contributing to the onset of depression symptoms. Additionally, given over half of the 168 patients sampled for the initial RCT were considered living in poverty, financial and employment burdens were also hypothesized as contributing to depression. When asked about causes of their depressive symptoms, participants did not struggle
for answers. Many offered precise origins for their depression. Below, the most common causes attributed to depression by participants are reported.

Physical health. The burden of physical illnesses was a contributing source of depression reported by more than half of the participants interviewed. Eleven of the 19 participants attributed their feelings of depression to the presence of physical comorbidities and these impressions did not vary by age or CIRS. Some of the participants mentioned not only having multiple illnesses causing their depression, the increasing severity of those illnesses causing feelings of distress and hopelessness.

I was depressed about my medical problems, I think it’s because, you know, I have arthritis, and its genetic and I think that you know, my condition has gotten worse. (F, 50-54, 20-24)

Well, I've been diagnosed with Addison's Disease. Quite a bit in the last year or two years. So with that, and not being able to work...being denied a few times for disability already, is very depressing. First of all I never thought I would be this sick especially this early in life, somewhat. And it is really debilitating. It makes life for me a lot more depressing... and I keep all my appointments, see all my specialists. And work here and just maintaining with medication. It is just not improving. And so having to deal with it every day, it is overwhelming. I am thinking at that time, that's when the diagnoses started. I mean getting one thing told after another that I had. And so that was the beginning of the snowball effect for me....I don't get a remission. So... Yeah. Pretty depressing. (F, 50-54, 15-19)

Pain. One of the more consistent comorbidities mentioned as a hindrance to participating and completing daily tasks was chronic pain. Chronic pain was also a significant contributor to the participants’ overall feelings about their current physical and emotional states. Participants mentioned feelings of hopelessness, failure, frustration, as well as the social and physical limitations as a result of living in constant pain, and as a causal factor for depressive symptoms.

Just this arthritis and this aching and not feeling good all the time, you can’t help but be depressed at times. (F, 50-54, 15-19)

And you know, it (pain) just causes depression. Sometimes my kids... It's like ‘my gosh. I can’t believe it’ and I start getting like real sick. And I can’t even hardly talk...you know, things that happened before and just...I don’t know. Trying to
think the right thoughts and try to help them and stuff. It bothers me a lot. (F, 45-49, 10-14)

But still again, those same things - the aches and pains and all that stuff - is enough to bring anybody down. So...I don't know if it brings me down to a point of being depressed, but I know it is certainly a downer to my feeling good. (F, 55-59, 10-14)

I think I was one of those people who was always waking up and feeling in pain and not happy with anything. Feeling hopeless. You know, I think that was me, you know...that’s depression...it doesn’t seem like anything is getting better (F, 40-45, 20-25)

Being in pain. It just puts your life on hold...it’s frustrating when you are in pain, you get depressed. (F, 50-55, 20-25)

For one, failure. And you know now that we are talking about this, that’s one of the times that the pain and all that kind of stuff started affecting my body. When I started going through some of the depression and stuff, and the loss and everything. It just felt like my whole body - not just my mind and my mood and everything - but my whole body physically was attacked. And um...I was so in pain all through my body. (F, 50-55, 5-10)

Two participants acknowledged a causal pathway between their pain leading to restrictions in their daily lives, then to feelings of sadness, frustration and depression.

Well, you know, I was depressed about my medical problems I was having and then I was depressed about that, and that’s how it came up. Being in pain. It just puts your life on hold. And so, that’s how it came up. It's frustrating. When you are in pain, you get depressed. Yeah. Well, when I'm in pain, of course I can't do certain things. Like my exercise is walking. It prevents me from walking if I'm in a lot of pain. So I get depressed. So that's one of my main problems. And it makes me very depressed. If I can't get out(side). If I'm in pain and I can't do certain things, I get depressed. And anyone who is feeling a lot of pain, I mean they get depressed. It makes you not want to do anything. It just frustrates you. Do you understand what I'm saying? (F, 50-54, 20-24)

Feeling pain all the time waking up. I don’t want to do anything. I’m not happy anymore. Just pretty doubtful (F, 45-49, 10-14)

Having multiple illnesses. While some participants mentioned specific illnesses contributing to their depression (e.g., pain), other patients explained their depression being the result of the frustrations, stresses, and difficulties associated with suffering
from multiple chronic illnesses. The feelings mentioned by participants are supported by the literature looking at complex patients. For example, many of the treatment interventions aimed at high-utilizers of health care resources did not address multiple conditions simultaneously and typically focused and “defined by single diseases”.

(Newcomer, et al., 2011)

*I have a lot of medical issues and I didn't think I was going to pull through a lot of them. And I think they had me just down and out, out of it... Like now. Every Monday, Wednesday, and Friday ...Ugh. I don't want to go to dialysis but I know I need it to stay alive.* (F, 55-59, 15-19)

*I have Emphysema. And it has kind of worsened as of today's date. Besides I am now a diabetic and I go to the doctor today. I don't know if they are going to start me on pills and I also have Glaucoma. So I got a few little stresses going on here, ok? (laughs) How I'm dealing with them, I'm just praying and just to be strong in this...It is hurting me.* (F, 60-64, 10-14)

*I had a total knee replacement. Hip replacement. I had hernia surgery a month ago. Well, you know, I also have hypertension. Uncontrollable hypertension. I had a stroke in my eye and you know, trying to keep my blood pressure under control. The list goes on. Plus I have arthritis, osteoporosis...being in pain. It just puts your life on hold. And so, that's how it (depression) came up. It's frustrating. When you are in pain, you get depressed.* (F, 50-54, 20-24)

One participant, when referring to how illnesses impact her overall health, stated “I am always in a state where my body hurts me” which illustrates the potential frustrations and stresses associated with being a complex patient.

Other participants reported causes of depression focused on the hassles associated with coping with depression and concurrent illnesses on a daily basis. Kanner et al. (1980) defined these hassles as the:

Irritating, frustrating, distressing demands that to some degree characterize everyday transactions with the environment. They include annoying practical problems such as losing things or traffic jams and fortuitous occurrences such as inclement weather, as well as arguments, disappointments, and financial and family concerns (emphasis added). (1980, p.3)

It is these, sometimes ignored, events that when they accumulate, can have a significant
impact on health outcomes important to understanding a patient’s illness narrative. Also referred to as life stress (Guthrie, 2014), this can both lead to depression and be an outcome of chronic illness, causing a vicious circle for complex patients.

Financial troubles. Eight of the 19 participants reported personal finances as a contributing to their depression. This was anticipated given the population studied is considered living in poverty and the stresses associated with finances can be felt daily and affect not only day to day to life, but also access to health care including physical and psychiatric care.

Well, depression ... well the stress is not being able to afford the rent but you still pay it. Ok? But you have to give up things. I have to choose my medications, you know? I can't keep the best medications but for a couple months a year, because of my deductible. And I have to settle for off-brand drugs and when I take them I get worse through the year and then after 2 months I can straighten back up with the good medications. And then I have to settle back down because I can't afford it again. That's a stress. Going around looking for a place to live, cause you can't afford where you live and the lists are like 2 years out every place you go, even for Senior Citizens. So you get stuck in a place you can't afford, but you have to deal with it. (F, 55-60, 10-15)

Cause they have things they want to do and I'm not able to do it money wise. So...I just don't do it. I don't. I don't know...it is kind of hard to put into words. I feel inadequate a lot. Just, I don't know. Why me, you know? Can't I have a little luck? A little stroke of luck? Can't I get one thing cured? Can't I just get enough money, which is my money, social security, so I can just be self-sufficient and not have to depend on others so much. (F, 50-54, 15-19)

Five participants mentioned not just financial struggles causing depressive symptoms, but the consequences of depression as it pertains to employment and normalcy.

Because I got sick and couldn't work and I'm used to working. And uh...I was really depressed when I got ...I knew it was a change in my life and I had to adapt to my new circumstances. You know? (M, 55-60, 20-25)

With my oxygen no one will give me a job. That's really the thing...instead of them looking at I really have the will to do it and I can pass all my tests, I just have this oxygen and it's in your face. And so that is a little bit of depression there. So it causes that no one is willing to give me a chance. And I guess that's it. (M, 65-69, 5-9)
You feel better about yourself when you are making money and you can do what you want to do and stuff like that. And not feel like people are helping me maybe when they don't want to. I don't like when people are in my situation, but I have no choice right now. Or putting them to the point where they have to help me or be outdoors. They don't want that for me and neither do I. (F, 50-54, 15-19)

...when I can't work. My body also doesn't allow me to do a 40-hour work week. And that in turn, has ...you know, I have very little income. I get (disability), which is 175.00 a month. Which is nothing. And it just makes me feel like I'm not...Well, I know I'm not able to take care of myself by myself. I'd like to be self-sufficient. So that is not happening right now and I don't know when. And that is more depressing. (F, 50-55, 15-19)

Just cause I couldn't do what I used to do before. And I don't...I don't make as much money as I used to before. You know, I used to be pretty active, but now I'm not active anymore. (M, 55-59, 20-24)

Family/interpersonal stressors. Additional stressors associated with daily hassles were those at the interpersonal level such as family or intimate partner relationships.

Two participants, when asked about their perception of the causes of their depressive symptoms, reported difficulties their social environments.

(My partner) stopped helping me with child support...I thought he would be there to help with my children, and he didn’t. I had to do it all on my own. So I think little by little I was getting into depression about it because when the girls were babies I used to cry a lot and them ‘what am I going to do?’” (F, 50-54, 5-9)

The first time I was ever pregnant - the first and only pregnancy I've ever had, I actually had a miscarriage. And the doctors told me it was due to stress...and the father of my child, during that week, did things above and beyond that stressed me out no end. And because of the way the miscarriage happened, they came to the conclusion that it was my PTSD that was the stress and the things that he was doing purposefully that week. (F, 35-39, 5-9)

A male participant attributed his feelings of depression to loneliness due to changes in family dynamics and a lack of communication with his children.

Yeah. So... but since I've gotten older and stuff and I'm by myself now. My kids are grown and I don’t really talk to them anymore. Or they don't call me. You know...I'm just pretty much by myself. (M, 55-59, 20-24)
Bereavement/personal loss. Of all the perceived causes of depression for those participants interviewed, the most commonly mentioned cause was bereavement/complicated grieving, with eight of the 19 participants mentioning death of a loved one as a major contributing factor for their depression. Often noted as one of life’s most stressful events, bereavement, defined as the grief that manifests from a traumatic event, in most cases death of a loved one, can potentially affect psychosocial, social, and physical well-being and increase the risk of major depressive disorders as well as suicidality (Latham & Prigerson, 2004).

Three of the participants shared specifically about the loss of a parent, both parents, or a child as a major contributor to their depression. Some of the participants had been dealing with their bereavement for some time and did not mention receiving any counseling or any other treatment to deal with their loss.

*I recently lost - well, not recently - but I lost my mother who I was very close with. Who passed two days before my birthday...So it was really terrible. It got the best of me. Cause I lost my mother. I didn’t have my mommy to go to. I didn’t have anybody. (F, 50-54, 5-9)*

*Because I been living like that for so long. That ain’t nothing new to me. You know what I mean? When I was first truly depressed was after my father committed suicide and I was 19 years old. Ok? That's when I noticed it was like I didn't want to live any longer either. And it's been since then that you know, it just...it's just always been there, so it is not a big deal anymore. You know what I'm saying? (F, 40-44, 5-9)*

*I first felt depression come on when I lost my daughter...I became a full-time parent to two small kids and my whole life turned around, so I was just stressed and lost and all that stuff just got me in a down place. (F, 55-59, 10-14)*

*I lost a son and it started my depression really bad. I couldn't cope with it. I didn't know how to cope with it. I had to get a lot of help to deal with it. It's been 10 years now and it still bothers me a lot so...yeah. It is a little bit better, but not a whole lot. But...it's pretty hard. Pretty rough...when I lost my son, it was just like I was hit by a train or something. It almost killed me like, I didn't know. I was like in shock. Like I didn't know what to do or how to deal with it. (F, 45-49, 10-14)*
Perceived Physical Symptoms of Depression

A significant component of understanding the patient’s illness narrative is how they describe symptoms of depression. Kleinman describes symptoms as a “kind of illness meaning” and these “meanings to be standardized ‘truths’ in a local cultural system” (Kleinman, 1988, p. 10). Given the significance local meanings have on illness descriptions, it cannot be assumed that patients descriptions will match clinical descriptions and this disconnect can impact the clinical encounter. Though it cannot be concluded that the patient’s somatization around physical illness is rooted in the psychological domain, many symptoms are the result of the “integration between physiological, psychological, and social meanings” (Kleinman, 1988, p. 14). Consistent with Kleinman’s assertion, when participants were asked about their perceived symptoms of depression, in themselves or others, described both emotional and physical responses, often concomitantly. Though the symptoms described by participants do not differ from how depression is clinically described including feelings of sadness or hopelessness, loss of pleasure participating or completing activities, reduced ability to concentrate, fatigue, changes in weight, and changes in mood, (American Psychiatric Association, 2000) participants shared an understanding of how they classify their symptoms and an grasp of how those symptoms perpetuate their adverse health status.

Nearly three quarters of the participants interviewed (14 of 19) focused on physical symptoms as indicators of depression with most among the males (three of the four) mentioning physical symptoms. A pattern also emerged by CIRS score with nine of the 10 participants with a CIRS score of 10 or higher reporting physical symptoms. Three distinct physical symptoms emerged from the interviews, though many had more than one type. Those symptoms are described below.
Exhaustion/Fatigue. Four of the 14 participants who mentioned physical symptoms contributing to their depression reported exhaustion or fatigue that is persistent and hinders participating in daily activities.

Being exhausted and not able to sleep...Just being exhausted all the time, Waking up exhausted and not getting enough sleep. And waking up during the night. (F, 55-59, 10-14)

I knew something was wrong but I didn’t know it was depression. I would have been saying I was just tired. For some reason, just tired all the time. You know. Not very happy with life. Just tired. (F, 45-49, 10-14)

One participant described feeling “sluggish” as a symptom along with apathy and negative feelings.

I don’t know. I don’t know how to describe it...not caring, sluggish...sometimes bad thoughts, not much to say. I can’t explain it! (F, 55-59, 15-19)

Pain. Another physical symptom of depression mentioned by participants was pain, not just as a cause of depression (discussed above) but also as a manifestation of being depressed. When comparing the causes and symptoms of depression, pain is a clear example of the bi-directional relationship between physical and mental health, both cause and effect.

Just the way I feel and stuff, it (depression) causes me the pain and stuff. Like in the mornings I wake up and sometimes I can’t get out of bed. And my legs are just like paralyzed and stuff like that. I can’t even move. So I just start and like it’s coming on with pain. And try not to think of things that are going on and happening in life. And you know that we are talking about this, that’s one of the times that the pain and all that kind of stuff started affecting my body. When I started going through some of the depression...it just felt like my whole body - not just my mind and my mood but my whole body physically was attacked...I was in so much pain throughout my body. (F, 55-59, 10-14)

Perceived Emotional Symptoms of Depression

Three distinct responses emerged from the interviews in explaining how participants perceive the emotional symptoms of depression. Along while describing the various emotions connected with depression, participants also mentioned the social and physical consequences of the emotional symptoms. Though the emotional responses reported by participants did not
deviate from the symptoms already reported in the literature, as well as the focus for instruments aimed at diagnosing depression, the results are reported here to offer context specific to this patient population.

Sadness. Five participants mentioned how the symptom of sadness equated to social isolation, as well as to a lack of motivation to be active.

*Being sad, not wanting to talk to anybody... you just want to be by yourself. You don't want nobody to bother you. That's how I think it means, you know, just wanting to be by yourself.* (F, 40-44, 20-24)

*Not wanting to do anything. Not motivated by anything. You know. Just sad... gloomy... It's everyday life for me you know... I mean I can tell cause I don't want to be bothered by nobody. I do want to do anything. I don't want to talk to people... I don't want to see people. I don't want to do anything.* (F, 40-44, 5-9)


*The main thing is I will cry at the drop of a hat. Not wanting to get out of bed. Not wanting to talk to people. Not wanting to be involved with anybody. There are a lot of little things that go on.* (F, 50-54, 5-9)

*Actually, I'm pretty depressed all the time. Cause I mean... there is nothing to look forward to.* (M, 50-54, 15-19)

*When you are depressed, you are more susceptible to colds and you just don't care and you don't take care of yourself, so you just don't... you know... Oh for sure. Not wanting to get out of bed, you know? So depressed and sad and miserable. I would stay in bed for a whole day. I don't eat. It's not good for you.* (F, 50-54, 5-9)

Hopelessness. participants also described their depression symptoms as feelings of desperation, hopelessness, and helplessness. These symptoms are not uncommon with depression and are including in many of the instruments to detect depression and other mental illnesses.

Referring to both depression in general and how it is experienced personally, one female participant expressed how depression has many symptoms, including desperation, but also how those feelings manifest into social isolation, negativity, and physical pain.
Well, what I understand it (depression) is feeling pretty low, that there is no help. Feeling pretty desperate. Feeling tired all the time. Not wanting to be part of anything. Just like living in your own little world...not wanting to be around too many people and not wanting to do too many functions and just not feeling good when you wake up every day- just not feeling good. Just mopey...if they are mopey. If they have a negative attitude where everything is always negative and stuff like that. They are not...you know...they are not happy. There is something going on, you know? I think I was one of those people who was from always waking up and feeling in pain and not happy with anything. Feeling hopeless. You know. I think that was me. You know. That's depression. (F, 45-49, 10-14)

For some of the participants, the feelings of hopelessness, and helplessness stemmed from having to cope with their illnesses, and difficulty of coping or accepting their situations contributed to defeated feelings.

So I might cry for a minute, you know? And then I have to pray. And have God just cover me so I can come back out of it, you know? Because I'm telling you. I do have times I sit down and there is nothing I can do. (F, 60-64, 10-14)

I just take my medications. Do my blood tests and do what I'm supposed to do, you know? There is no cure for what I have. I mean there are things that suppress it or ease it up. But it's there and it comes back so...it's just...I don't know. Again, you know, I hate to keep saying Why me? But it is like just so much. Why do I have so many things going on? I don't get a remission. So... Yeah. Pretty depressing...my illnesses keep me down. Depression keeps you down. So it is just a different form to me. It is just another added on disease, so to speak. (F, 50-54, 15-19)

**Living as a Complex Patient**

In addition to understanding how patients describe symptoms as part of their lived experience with depression, questions were included to elucidate life experiences as a complex patient, particularly how having multiple chronic illnesses affects a patient’s quality of life (QOL) (SA3). The purpose for better understanding how patients see the relationship between their illnesses and their QOL are two-fold: First, to recognize how having illnesses in both domains affect the indicators associated with QOL (e.g., day-to-day life experiences). For example, if a patient is ill and does not want to socialize though healthy social interactions are associated with improved health outcomes; now there is a cycle contributing to adverse health. Second, to better
inform clinical interventions aimed at depression symptom improvement about the day-to-day consequences of being a complex patient and how opening dialogue concerning those consequences could lead to better outcomes. For example, if patients identify a lack of motivation to engage in social interactions, and given the influence socializing has on health outcomes (Kawachi & Berkman, 2001; Thoits, 2011) both clinicians and researchers working with complex patients could include aims at increasing social interactions and community engagement.

For the purposes of this analysis, the themes around quality of life were derived from the literature that focused on functioning, well-being, and the patient’s subjective perception of their day-to-day life experiences (Mendlowicz & Stein, 2000). For complex patients, dealing with multiple health problems has social, physical, and behavioral implications. Having multiple illnesses concurrently is associated with being more functionally impaired (Vogeli, et al., 2007), and when certain chronic conditions are experienced with a mental health problem, there is a significantly lower quality of life reported (Mujica-Mota, et al., 2015). When asked about their own assessment of their quality of life, participants interviewed shared a similar experience, expressing feelings of frustration, high levels of stress and anxiety, and feelings associated with depression.

A common connection made by the participants when asked about the relationship between their mental and physical health was the limitations and hindrances caused by dealing with illnesses in both domains on daily activities. The responses around daily functioning were focused on physical or social functioning or in some case a mix of both.

**Physical functioning.** Participants described an inability to participate in activities viewed as a large part of a person’s normalcy such as house duties, walking, daily exercise routines, and hygiene practices. In describing how physical functioning is affected by illnesses, including depression, shows the participants comprehension of the bi-directional relationship
between physical functioning and mental illness and how daily activities are important to their quality of life.

One participant mentioned how they associate their physical activity/functioning with normalcy, being a “nobody” in society and how the loss of being able to do basic, everyday activities is a determinate of their self-value.

Of course it (physical health) affects your mental health, you know? When you go from being a very active, productive person in society to a nobody, who can barely take care of yourself. Of course that affects you mentally. What can you do without your hands? Not much. Before long I won't be able to cook. I won't even be able to wipe my own ass. What do you think it would be? I mean come on!...you can handle anything when you are able to function like a normal human being. I mean ...I just think about one day being on top of the world you know? And training for a marathon...walk and run around the lake a couple times for my training. And then one day it stopped. It all stopped for me...if I could do all those things again - hell when I'd get upset I'd go for a run. If I was depressed I'd go grab my bike and go for a couple mile bike ride you know? So yeah.

Getting rid of the pain would be an awesome thing. (F, 45-49, 10-14)

The following participants shared how they view the bi-directional relationship between physical and mental illness, for example no sense of enjoyment, loss of autonomy, and mostly how limiting their illnesses are and the frustrations they experience because of it.

Well, it slows me down, that is a prime example of mental/emotional over physical... I still want to do things I want to do and need to do. I still try to do those things. Whether it is chores or taking walks to the park, walking the dog, really nice things to do, but yeah. It just slows me down. I get tired easier. Um...thirsty more often. Sweating a lot more because everything slows down. I get exhausted. (F, 35-39, 5-9)

...mental health affects my physical health is from the pain because I can't, you know, do certain things and it just frustrates me. It's like getting older. So shoot... it sucks! Well, when I'm in pain, of course I can't do certain things. Like my exercise is walking. It prevents me from walking if I'm in a lot of pain. So I get depressed. So that's one of my main problems. If I can't get out, if I'm in pain and I can't do certain things, I get depressed. I do nothing. I just like...I don't know what other people do, but I just like sleep...because the pain doesn't allow me to do certain things And anyone who is feeling a lot of pain, I mean they get depressed. It makes you not want to do anything. It just frustrates you. Do you understand what I'm saying? (F, 40-44, 20-24)
Well, I used to be able to walk around the block before I got sick. I was walking
around my block you know? Walking around and I walked around and I can't do
that now. And then now I have Osteoporosis and my back and my bones. My
wrist would shatter really easy. . (M, 55-59, 20-24)

I mean it is just like a struggle to get out of bed. A struggle to do what you have
to do. Shower. Take your medications. You know...be active. Try to be active
with others and stuff like that. (F, 45-49, 10-14)

Day-to-day activities. When talking about having multiple conditions, three of the
participants connected their illnesses with a diminished interest or incapacity to do day-to-day
activities in a more general sense. Though similar to some of the findings associated with
physical functioning, these participants mentioned a diminished sense of motivation in a general
sense and not necessarily specific activities.

It (being depressed and physically ill) just makes me not want to do anything. (F,
45-49, 10-14)

Well, some days I just don't feel like doing nothing. So...if you don't feel like
doing anything that can affect you physically because we are designed to move.
(F, 50-54, 10-14)

It (having multiple illnesses) bothers me a lot. I have a lot of pain through the
day. And I don't know...it is hard to get stuff done. I take my medicine and it
helps me get stuff done. And I have diabetes so I have to kind of watch what I eat
and stuff. It's not easy, you know? I don't know. I've had diabetes for over a year
and then I take medicine for that, twice a day. (F, 45-49, 10-14)

I just ache like that all the time...You know. I do what I do and come back home.
If I don't, you know...for instance I had a better offer today than the sale
yesterday. And now I wasn't able to do it because now I don't feel like it first of
all. And I know if I get out there, I'd be having to deal with my leg. Dragging my
leg all over town. I'm not going to do that. I don't do very much. I mean I do the
same thing. If I don't feel like doing it, I'm not going to do it. And it ends up being
90% of my daily living. It really does. Cause if I don't want to do it, I'm not going
to do it. If I don't want to do it the next day, I'm still not going to do it. So it
just...I don't do it. I don't do anything. Oh, I'll take a shower every day. Well, two
or three times a day sometimes. But like I comb my hair. I do change clothes. I do
make my bed, but that's about it. (F, 40-44, 5-9)

Social functioning. Though participants tended to focus on how having multiple
illnesses impacted their physical health and diminished their quality of life, when asked about the
social implications posed by depression (and in some cases in conjunction with other illnesses), participants often mentioned feelings of social isolation and having little to no motivation to be around others.

Eight of the 19 participants interviewed talked about how having multiple conditions along with depression can lead to social isolation. When referring to the effects of having to take various medications to control her illnesses, one 50-54-year-old female expressed how having to see her doctor frequently, she does not get out of her home very often and “with my medicines, some of them make me not able to get up...and do things…it’s just not a good thing at all.” Two patients talked about having to hide her depressive feelings and manifestations from friends and family.

*I mean, you know. There are times that you got friends that call and they want to do something and you just don't want to do it. I just kind of keep a smile on and don’t say much of anything and just try to be cheerful you know? And when it's time to go into another room, I go into another room and cry and let it out and stuff like that...It (depression) just makes me not want to do anything. It just makes me not really want to do much of anything. Other than just stay by myself, other than just be alone. (F, 45-49, 10-14)*

*You know...it is hard and around family, you have to put that happy face on and try to act normal and it's hard. It's hard…(F, 45-49, 10-14)*

One male participant described how his physical illness made him feel like a burden, therefore limiting his social time with family.

*Sometimes my brother might invite me to their house and I kind of get a little irritated because I'm on that oxygen and which I could go. But I don't have a ride. And I don't like bugging people to give me a ride. Give me a ride. Cause my oxygen, to carry it, it only holds so much oxygen, a couple hours or so. And then, you know, I start running out. Then I kind of panic because I'm running out of oxygen see. And I got to get back on. And stuff like that. So I get really irritated about that. (M, 65-69, 5-9)*

Other participants expressed various ways depression (and other illnesses) pose social challenges including how their mood impacts their interactions, staying in their homes from extensive periods of time, and just a constant feeling of not wanting to be in social situations.
Um...Well, I don't know what to say about that. But I do notice when I am really stressed and depressed a lot, I won't go out the house. And sometimes it is hard to come out the bedroom. And that could last. That lasts for a little while, you know? Until I can break myself out of it. It doesn't last for like a week, you know? Because I make myself get up...and it gets hard cause it is like I can't walk. Sometimes it gets that way, where I can't walk, but I don't know if that's from the diabetes or what? I'm fine today. (F, 60-64, 10-14)

It does. It does. I try to say...I'm always happy when I'm out in public. I put my best food forward. I don't let the mood swings get me too much. Sometimes when I'm alone the mood swings come out. Or they come out at home around my dear ones. I don't let everybody see it, but I have mood swings and I got to get me some mental health. (F, 50-54, 15-19)

And I think they (illnesses) had me just down and out, out of it....I can't do a lot of planning, By the time I get ready and get done with dialysis, most of the time I just have to come home. And lay down. Go to bed early. (12)

Five of the participants felt that interactions with others were bothersome, both because they were made aware of their limitations because of their conditions and seeing people reminded them of that, or because their current health state negatively impacted any desire to interact socially.

It means that I don't feel...let's see how to put it. I don't want to do anything, I mean I do. But knowing I am not able. And since I can't, I just shut in. You know what I mean? I mean I can't do it anyway. So...I just...plus I'm an only child. So I was always by myself, so I'm used to being by myself. And that was what I would prefer to do. I mean I'd like to be able to get out, but knowing that I can't just makes me depressed more. So...it looks bad. I don't have suicidal thoughts. I am not on that road. I'm just on the self-mode. Closed in. Like pretty much don't want to be bothered with anybody, because you know, I can't do anything with them. And I'm not going to have people come and visit me all the time cause I don't want to get out. You know what I mean? (F, 50-54, 15-19)

It is everyday life for me, you know? I mean I can tell cause I don't want to be bothered by nobody. I don't want to do anything. I don't want to talk to people. I don't want to see people. I don't want to do anything. (F, 40-44, 5-9)

I'm just wanting to cave and not be around people. Or it would be fine with me if I didn't even have to associate with people. (F, 55-59, 15-19)

If my legs worked properly or if I didn't have a constant ache in my back. You know what I'm saying? It goes throughout my legs and it's been doing this for quite a few years now. So...I mean I don't really want to do anything. I have to
take pain medication of course. And when you are on that in high doses, like I am, what if I'm out in the public and something might happen? Cause I know I'm not there. You see what I'm saying? (M, 55-59, 10-14)

Well, I don't know what to say about that. But I do notice when I am really stressed and depressed a lot, I won't go out the house. And sometimes it is hard to come out the bedroom. And that could last. That lasts for a little while, you know? Until I can break myself out of it. It doesn't last for like a week, you know? Cause I make myself get up. And it gets hard cause it is like I can't walk. Sometimes it gets that way, where I can't walk, but I don't know if that's from the diabetes or what? I'm fine today. (F, 60-64, 10-14)

Response to Research Question 2

**How do medically-indigent depressed patients describe their lived experience with concurrent illnesses?**

When describing their lived experience with depression and often multiple coexisting illnesses, participants were able to articulate their experience with depression, giving insight and voice to their experience, providing a useful narrative for clinicians to use for treatment and communication (Barry, Stevenson, Britten, Barber, & Bradley, 2001). Participants described a variety of causes for their depression including those hypothesized including coexisting illnesses (living as a complex patient, further explored later in the chapter), and financial and employment burdens. Other causes emerged from interviews including factors like bereavement, and family/relationship stress. When describing symptoms of depression, participants by and large reported those factors used as proxies in many of the instruments to measure depression, including feelings of hopelessness, fatigue, and sadness. Though not all of these factors were reported by a majority of the 19 participants interviewed, the disparities show a need for being more responsive to personal narratives in the clinical encounter, aiding personalized treatment for depressive symptoms.

Participants’ responses around life as a complex patient presented a rich representation of how the participants’ day-to-day lives are impacted by their health. Their descriptions offer an understanding of cyclical relationship between their physical and mental health, how it impacts their social and psychosocial health, and in turn adds to their depression symptoms. The
participants mentioned a loss of self-value with losing their capacity to participate in daily activities often viewed as important proxies for normalcy.

Research Question 3

This portion of the qualitative analysis aims to answer the third research question, *how does a diagnosis of a new episode of depression change the management and prioritization of concurrent illness for complex patients?* This set of questions looked at how patients manage and prioritize their illnesses. Themes emerged providing some detail to how illnesses are treated, prioritized, and the competing demands and barriers patients identify that hinder physical and depression symptom improvement.

Illness Priority

In analyzing interviews, a salient theme emerged related to how patients prioritize illness treatment after a new episode of depression. Participants mentioned priorities for both themselves and their providers. Given that patients and providers were aware of the new diagnosis of depression prior to the first visit while participating in the RCT, it was hypothesized that depression would become a treatment priority, and though patients were interviewed after the completion of the RCT, remain a priority even after the completion of the RCT. However, when asked about which illnesses the patients and providers prioritized, the majority of the participants interviewed were more likely to report that their physical ailments took precedent over their mental health.

Patient treatment priority. When discussing their own illness priorities, participants mainly focused on physical ailments. One female participant was explicit about not wanting her depression symptoms to be a priority for her health care stating, “I don’t go to doctors for my depression”. Two participants mentioned that they prioritized their physical illnesses mainly because they have learned to live with their mental health conditions.
No I was just thinking. I'd have to say my weight. Blood work is always good. I'm healthy on the inside. So it is my weight. It hurts my joints and impedes on my life more than anything. My mental health - I make the choice to be happy and I make the choice to look for the positive and the good. So I'm aware and in control of my mental health, is the best I can do. But the PTSD - I don't even notice it sometimes. I'm sure other people notice it first. But yeah, I think it's just the fat to be honest. (F, 35-39, 5-9)

Probably the other issues... the problems with my hands...I'm slowly losing the use of my hands. What can you do without your hands? Not much. Because like I said, my depression I've had so long that it only becomes a problem on occasion. (F, 50-54, 5-9)

Some participants were adamant about their physical health taking priority when it came to treatment. Two participants in particular viewed the relationship between their physical and mental health as hierarchical.

I think physical. I would treat my physical before I treated my mental. Cause I think my physical has a lot to do with my mental. I think if I were to go to...I have my recreation card... I think if I were to go to the recreation center a little bit more, when I get in those depressed states; I think if I would go and work out, it would help a lot. So that's why I say my physical probably would overrule my mental. (F, 50-54, 15-19)

I think probably physical health. That's the main thing. I been going through a period of depression. And um...but I'm feeling a lot better, at this point. So I think the muscular stuff is probably the main thing. Um... for 1) I think if my physical health were improved, then I would feel better on a daily basis and do a lot of different things that sometimes I'm not doing because of the health issues. (F, 55-59, 10-14)

One participant mentioned specific physical illnesses as treatment priorities.

My physical, I guess. Like now, every Monday, Wednesday and Friday ...Ugh. I don't want to go to dialysis but I know I need it to stay alive. So... And the fact that my diabetes has my eyesight ...I can't see at night. (F, 55-59, 15-19)

Provider treatment priority. participants also described which illness(es) their providers prioritized. The most common response given by patients was that mental health was not a priority. Though providers were aware of their patient’s depressive symptoms, participants did not always believe it was their provider’s priority. An obese participant mentioned that her provider was aware of her depressive symptoms but still focused on her weight problem, “she’s trying to control my weight because the weight is what is making me depressed”. Two
participants described there being no discussion around mental health because of other health problems to manage.

Pretty much when I call to make an appointment, we pretty much talk about the things I think are important. The last time I talked to him it was for...what did I? Oh, they thought I might have...what do you call that? They thought I might have a hernia! Well, right now we haven't even discussed it (depression). We haven't had no discussion in a long time. It is well over a year. I don't think we've even discussed it (depression). We've been focused on so many other things. (F, 50-54, 15-19)

That’s to the forefront. I got other issues of course, but we ain't really worried about those. It is just getting through this pain on a constant basis, all day, every day. (F, 40-44, 5-9)

Another participant seemed open to changing her priorities and discuss her mental health but did not want to trouble her provider so focused on the “main issues” as not to take up too much time.

Yeah, well, she (primary care provider) basically prioritizes whatever is happening with my health at the time. You know? And she sends me for tests and all of that. I don't... I don't feel like I want to put that (depression) on her a whole lot. Because she has so many patients that she needs to deal with as well. So I don't want to take up a lot of her time, even though she would be willing to sit there with me. But I just don't want to take up a lot of her time. You know? Just sitting back and discussing everything that is going on with me, I just go in and I want her to take care of my main issues that are going on with me, like pain and all that. (F, 55-59, 15-19)

A male participant mentioned that his provider’s main concern was preventing a heart attack and was focused on managing his energy exertion in the workplace.

Not really any other illness. Well...I think my doctor, he doesn't want me to work. Cause he says... he used to tell me he was worried about me having a heart attack. You know? Because of in my body...he was afraid I would push it too hard. (M, 55-59, 20-24)

**Depression Treatment Preferences**

A particular salient finding from the qualitative interviews was that more than half of the participants interviewed did not want to be treated for depression in a primary care setting.

Twelve of the 19 participants interviewed shared their preferences ranging from seeing a therapist/counselor, to social support.
Spiritual/prayer. Three of the 12 participants shared how spirituality, specifically prayer, was an important modality for self-treatment for their depression.

*I just don't want this to defeat me. You know? And I'm sure that my faith helps me to get up in the morning, you know? I don't want to give up regardless of my stresses and my circumstances. I just...just have faith. I'm going to still keep my faith and I'm still in faith for recovery, you know? That's how I recovered from this diabetic thing. I just...I'm just going to do what it takes to try to alleviate it. You know? And it helps with my stresses and my circumstances and my depression. You know? I don't take medication for it. I just have to pray. Pray and praise. That's me... Yes. It helps a lot with the depression. It helps a lot with the stresses. If you can get your mind off of yourself. I learnt that since I been on that study. I learned how to try to just go about it another way. Read to enlighten myself. But I'd say I'm doing much better in my depression and stresses than I was. Cause I have a lot...I am in a place I can't afford but I can't find a place to live. Ok? But I have to keep positive that sooner or later something is going to happen. Well, I guess Jesus. Because I found the faith you know? I've got something else to release my thoughts to. And it is helping. My faith is helping me.* (F, 60-64, 10-14)

*I start praying and I pray every day. I don't get to church every week like I should because of the oxygen and stuff. But I pray every day. And my problems and whatever, I leave it in the hands of God. Let him take care of it. And so far, he's been taking care of me.* (M, 65-69, 5-9)

Family support. Three participants mentioned support from a family member (one mentioned it in conjunction with prayer) as a way to deal with his depression symptoms.

*Well, being a Jehovah's Witness, of course, I pray about it. And I have many friends that I can talk with and I know...you know...when I talk with my friends, that's what happens when you are depressed. You got to have some way to vent. And I have people that I can talk with. And then I have my oldest son, you know? My relationship with him is where I feel comfortable in talking with him.* (F, 50-54, 10-14)

*I have friends and family that help me out.* (F, 50-54, 15-19)

*Well, actually, I did have a lot of depression, but now I'm a lot better. I learned to just like walk and pretty much and talk with family and that makes me feel better. It was bad. But then I had to snap out of it though. From feeling sorry for myself. And make myself a better person. Getting out of the house. I go walking to the park with my son. Just having a good day.* (F, 40-44, 20-24)
Professional treatment (not primary care provider). Three of the twelve participants mentioned wanting to get professional treatment for their depression in the form of counseling or therapy.

_Grief Counseling. It did. Yep. It helped. It helped. It helped a whole lot. It was just that every year when that month comes around it seems like I go --- try to go into it, depression, again. I do counseling with my Pastor too._ (F, 55-59, 15-19)

_Oh, therapy. I don't believe in prescription drugs._ (F, 35-39, 5-9)

_I get counseling and stuff. And just talking to people and opening up instead of closing down and stuff. Just trying to talk to somebody about it. And it helps me... Breathe and stuff. I try to breathe._ (F, 45-49, 10-14)

**Opposition to medications.** Two participants expressed a strong opposition to medications for depression, both had first-hand experience with anti-depressants but either had their provider take them off the medication or expressed concerns about their current medication regime.

_I wish I didn't have to take all these pills. And like before. I was taking the wrong kind of medications for my depression. I would sit there and count my pills I don't know how many times. Cause I don't know, that particular pill seemed to be affecting my way of thinking. Because it was interfering with concentration._ (F, 55-59, 15-19)

_I just had him take me of my medication because I'm better without the medication._ (F, 50-54, 5-9)

These findings suggest that some participants experiencing a new episode of depression do not want to be treated in primary care settings for their depression, which can be problematic for interventions in these settings.

**Primary care/medication.** Not all participants interviewed were opposed to their primary care provider providing depression treatment or to taking medications for their symptoms. When asked about her treatment preference, one female participant expressed, “I would love for him (primary care physician) to treat it. That would not be a problem.” Another could not see why a medical doctor would not be responsible for mental health care.

_I don't think you separate them. I've often thought that it is ridiculous that you have to see a therapist aside from your medical doctor. I think medical doctors in_
general should be trained in the psychology part of their patient's lives. I just
don't see how you can separate them. You really can't separate any of it. (F, 35-39, 5-9)

Two participants reported either being open to medication, or were currently taking medication for the depression symptoms.

I figured I'm depressed and know I know what is going on. We can do medications. We can try to get this under hand and maybe everything, you know, will look a lot brighter. You know, everything won't be so gloomy. (F, 45-49, 10-14)

Well, the drugs don't hurt. They help a little. But I try to keep my mind, these days, where I just don't even think about the depression thing. You know, like not having something, or stuff like that. I just don't think about it. So that's about it I think. (F, 55-59, 15-19)

**Competing Demands/ Barriers to Treatment and Improving Symptoms**

Competing demands is defined as the factors that pull patients and providers in many directions and include but are not limited to, personal demands from family and friends, discrepancies in medical information, financial burdens, conflicting agendas of care, concurrent illnesses, employment demands, transportation, and time constraints (Jaen, et al., 1994; Klinkman, 1997; Nutting, et al., 2000). Though research has looked at these demands and how they impact the clinical encounter, most research has focused on the demands in the clinician domain (Klinkman, 1997; Nutting, et al., 2000; Rost, et al., 2000; Stange, Fedirko, Zyzanski, & Jaen, 1994; Williams, 1998). For the purposes of this study, participants were asked about if and what factors impeded them receiving care, opening dialogue about, and starting and maintaining a treatment regimen for their depression symptoms. It was hypothesized that because the participants interviewed were dealing with concurrent illnesses, that competing illness would be a significant factor competing with depression care. Three main demands emerged from the interviews and are described below.
Concurrent illnesses. As predicted, concurrent illnesses was a common competing demand described by the participants interviewed. Seven of the 19 participants reported trying to manage their various illnesses, other than their depression, as their primary priority.

That’s to the forefront. I got other issues of course (she mentioned depression earlier in the interview), but we ain’t really worried about those. It is just getting through this pain on a constant basis, all day, every day. (F, 40-44, 5-9)

And I'm always…I guess in a state of where my body is always hurting me. (F, 55-59, 15-19)

One participant described weight as her main concern, “stopping” her from pursuing treatment for her depression symptoms and causing other health problems exacerbating the demand put on by the weight.

What gets in the way? Being overweight. That stops a lot of things. You know, I have ...the overweightness has brought on arthritis in my knees, fluid on the knees. I'm just falling apart over here. (F, 55-59, 15-19)

When asked about her competing demands, one participant answered by listing her illnesses as her answer.

Degenerative joint disease, asthma, vertigo. What else? Sciatic, weakness in the knees, carpal tunnel, rotator cuff injury, clavicle injury, arthritis throughout the joints in the body...I think that is pretty much it. There might be a few more I left out, but I don't know. (F, 50-54, 15-19)

Family/social relationships. Seven of the 19 participants interviewed mentioned their family or other social relationships as taking priority over seeking treatment not only for their depressive symptoms but also for their overall health care (often along with other demands). One participant described that her overall health was not prioritized stating, “I basically put my health off for somebody else's needs…I have experienced that quite a few times.” Another shared an experience that occurred the same day she was interviewed where other commitments tended to take precedence over seeking care, in this case for her depression.
I was going to call today (mental health counseling), but I didn't get a chance. My daughter came and I ran around with her and my granddaughter...but I had that on my list of things to do today...to call and get an appointment with mental health. (F, 50-54, 15-19)

Along with family commitments, two participants also shared additional competing demands impeding their own care. One participants not only mentioned her son’s health as a priority and her relationship with him, but also grief, and her own competing illnesses as not only competing with seeking care for her depression, but also the reasons to not accept her depression symptoms.

Well, my parents passed away. My son being sick. He has Spina bifida - the closure of the spine and that was bothering me too. And I'm epileptic so that bothered me a lot, you know? Now I have to deal with it. So it's not going away. Make the best of it...I been epileptic since I was 13 years old. Just you know, try to deal with life, you know? Cause I figure like my son, you know, he doesn't need to see me being depressed and being sad and all that. He needs his mom. He needs me to be there for him. Being depressed is not worth it... No. No. I get...I come into my room and I'll want to be by myself and I won't to see my son and he gets sad because my son tells me, I wish I could walk like my friends. And it makes me sad. But then you know, I have to think, my son can do some things in his wheelchair. Just you know, try to deal with life, you know? (F, 40-44, 20-24)

Similarly, another participant mentioned the health of a family member as a priority, but concurrently she is dealing with competing illnesses, financial problems, and desire for independence.

She (mother) has early stages of Alzheimer's. So I have to make sure she gets to her doctor's appointments and get what she needs as far as hygiene and all that kind of stuff. So, I think between that and doctor's appointments and stuff, I keep as busy as I can. Now I'm getting ready to have surgery on my rectum. So...Yeah. I need to have my other knee done. I had one knee replaced already. They are ready to do the other one. And so... Cause they have things they want to do and I'm not able to do it money wise. So...I just don't do it. I don't. I don't know...it is kind of hard to put into words. I feel inadequate a lot. Just, I don't know. Why me, you know? Can't I have a little luck? A little stroke of luck? Can't I get one thing cured? Can't I just get enough money, which is my money, social security, so I
can just be self-sufficient and not have to depend on others so much. (F, 50-54, 15-19)

Finances. Another type of competing demand mentioned by the participants was concerns about finances including costs of care (e.g., medications, and insurance), and daily living, in some cases not only hindering seeking depression seeking behavior but also adding to the feelings of stress and hopelessness.

Well, first of all cause I ain't go n' money to plan with. So basically, it is not just my health issues, it's financial issues as well. So... (F, 55-59, 15-19)

It is money that comes up. For me it's money. Because for me to treat all 3, the emotional, mental and physical...It's so hard to balance it because the money is just not there. And you have to work for it and you have to take the time away from what is really important and put it into your job. I'd have to say money and time. (F, 35-39, 5-9)

When asked about the demands affecting their health outcomes, two participants talked about how the cost of health care and insurance along with other environmental stresses make it difficult to focus on treating their depression symptoms.

I have to choose my medications, you know? I can't keep the best medications but for a couple months a year, because of my deductible. And I have to settle for off-brand drugs and when I take them I get worse through the year and then after 2 months I can straighten back up with the good medications. And then I have to settle back down because I can't afford it again. That's a stress. Going around looking for a place to live, cause you can't afford where you live and the lists are like 2 years out every place you go, even for Senior Citizens. So you get stuck in a place you can't afford, but you have to deal with it. Cause I take so much medication, I take so much medication it will run circles around me ok... And now they put me on more medication with my Glaucoma and stuff. (F, 60-64, 10-14)

One participant prioritized finding ways to pay for her medication for her pain, though she was suffering from multiple illnesses including depression.

So it's like my deductible is paid... so I can start taking the good stuff (pain medication) again... Well, I won't take it until I get my deductible paid down. When my deductible is paid I can get a 3-month packet of that for like 90.00 ok?
Response to Research Question 3

How does a diagnosis of a new episode of depression change the management and prioritization of concurrent illnesses for complex patients?

The responses around the prioritization and management of the patients’ illnesses did not align with the hypothesis originally purposed stating that patients dealing with a new episode of depression would want to make treating those symptoms a priority. Both patients and providers continued to focus on physical ailments and controlling existing disease. When discussing their treatment for depression symptoms, participants offered several modalities preferences including medication, prayer, social support, and counseling/therapy. One emergent theme from the treatment preferences was participants did not want to initiate or continue a prescribed medication regimen for their symptoms either because the patient was already on enough medications for other illnesses, or because they did not believe it offered any relief. Responses to which competing demands impacted depression treatment seeking behavior focused on three types, competing illnesses, social relationships, and financial burdens, some a mix of different competing demands occurring simultaneously. The code counts for each category are reported in Table V.2.
### TABLE V.2: Total Counts of the Codes Identified

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<th>1. Patient Demographics (code)</th>
<th>Totals: 27</th>
<th>Total interviews (number of patients) 19</th>
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<tbody>
<tr>
<td>2. Patient Overall Health</td>
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<td>5</td>
</tr>
<tr>
<td>3. FAM-Clinical Encounter</td>
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<td>3. Communication/treatment preferences</td>
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<td>3. Discussion around mental health</td>
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<td>13</td>
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<td>3. Initiating Priorities</td>
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<td>1</td>
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<td>3. Medications</td>
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<td>4</td>
</tr>
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<td>3. Negative Response to RCT</td>
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<td>5</td>
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<tr>
<td>3. Positive Response to RCT</td>
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<td>3. Provider Inquiry (Clinical)</td>
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<td>0</td>
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<td>3. Time with provider</td>
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<td>4. FAM-MH-&gt;PH Relationship</td>
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<td>4. Medications/Side effects/combination</td>
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<td>4. Physical Health Hindrance</td>
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<td>6</td>
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CHAPTER VI
DISCUSSION

Depression is a difficult disease to diagnose, treat and often left out of clinical dialogue between patient and provider (Weihs & Wert, 2011); and it is responsible for significant functional impairment and disease burden globally (CDC National Center for Health Statistics 2013), high utilization of health resources (Hasselman, 2013; Guthrie, 2014), and overall medical costs (Katon, 2011). Because of deleterious effects caused by depression, better interventions are necessary to improve depression diagnosis and treatment, including those that address its co-occurrence with physical health. Increasingly, it is recognized that depression symptoms occurring concurrently with chronic illness conditions can increase the severity of medical illnesses (National Institute for Health and Clinical Excellence (National Institute for Health and Clinical Excellence (NIHCE)), 2009), as well as contributing to more somatic complaints during primary care visits (Thielke, Vannoy, & Unutzer, 2007). Additionally, given the ubiquity of antidepressant prescriptions, specifically SSRIs, interventions aimed at developing treatment strategies either in conjunction with, or as an alternative to, prescribed medications are imperative given that the presence of physical health disorders can lead to complications with interactions with other medications, and the potential of antidepressants exacerbating chronic illnesses (National Institute for Health and Clinical Excellence (NIHCE), 2009). This phenomenon referred to as “polypharmacy” also includes the common reaction from health care to medicalize patient’s unhappiness and to recommend a pharmaceutical treatment regimen (Stanners, Barton, Shakib, & Winefield, 2012).

When setting out to examine the potential effect of coexisting illness severity on depression symptom improvement, I hypothesized patients with less coexisting illness severity (CIRS score)
would see greater depression symptom improvement compared to those patients with high illness severity. I also sought to illuminate the bi-directional relationship between depression and chronic illness particularly the relationship between depression and the management and prioritization of coexisting illnesses (e.g., competing demands), particularly because the research regarding competing demands and depression is mixed (Ani, et al., 2009; Klinkman, 1997; Nutting, et al., 2000; Rost, et al., 2000; Vyas & Sambamoorthi, 2011). The goal of the qualitative phase of this dissertation research was to add to the understanding of the lived experience of patients with depression, including how depression and other illnesses impact their daily living, and their treatment priorities, addressing an important gap in the literature about depression in complex patients (Stanners, et al., 2012). The hope is that these findings can inform both the assessment and treatment of depression in the context of co-morbid chronic conditions and complexity of issues that emerge in the lived experience of medically-indigent complex patients. This dissertation study sought to help fill additional gaps mentioned in the literature concerning depression among complex patients.

**Change in Depression Over Time in Complex Patients**

Though the original RCT was not designed to look at illness severity as a potential predictor for depression change over time, the patients approached for the study were not excluded because of their current or past physical health conditions (only if they were currently on a depression medication regimen), affording the opportunity to look at the medically ill and their response to a depression intervention, historically a population not always included in depression interventions (Koike, Unutzer, & Wells, 2002). Though most of the research on multimorbidity and depression does mention higher prevalence of depression among those with chronic conditions, (Bair, Robinson, Katon, & Kroenke, 2003; Benton, Staab, & Evans, 2007; Clarke, 2009; Koike, et al., 2002), for this study those patients with moderate to high CIRS had higher PHQ-9 scores at each time point suggesting a relationship between physical illness.
severity and depression severity. This also potentially supports the claims of the bi-directionality of depression and physical illness (Evans & Charney, 2003; Evans, et al., 2005).

Though I hypothesized that complex patients with high levels of chronic illness severity would experience significantly less depression symptom improvement over time and would be less responsive to the RCT than those with lower illness severity, there was not enough observed variation in the scores over time to test this hypothesis adequately (Raudenbush & Bryk, 2002). The HLM analyses of the relationship between illness severity and change in depression over time did not vary significantly across the patients in the study. Though the findings do not refute the relationship between illness severity (rather than simple counts) and depression symptom improvement, it cannot be inferred that illness severity is a causal mechanism hindering depression improvement (Benton, et al., 2007). What did predict depression change over time was baseline PHQ-9 score; though intuitively this would be due to patients experiencing more severe depression at baseline have a larger range of potential improvement. These findings suggest an important need for future research to test for potential factors contributing to depression symptom improvement in primary care settings.

**Key Findings from the Qualitative Analyses**

In contrast to quantitative findings, the qualitative portion of this work offered a rich description of how patients with multiple chronic conditions describe and live with depression. Patients openly described how depression impacts their quality of life, their coexisting illnesses and current health status, descriptions of what they consider to be the symptoms and causes of depression, and how they prioritize their treatments and the competing demands that hinder receiving or maintaining treatment for their depressive symptoms.

**Patient Description of Depression**

One of the factors contributing to the difficulties behind diagnosing, discussing, and treating depression for patients with multiple chronic illnesses is the myriad causes for depression
as well as how depression is described (symptoms). Unlike most chronic illnesses, the causes of depression are many and experienced differently depending on the individual, as are the symptoms, which do not always sync with clinical descriptions of depression. As expected, the patients interviewed described their physical health as one cause of their depression including their overall physical health (e.g., having to live with multiple illnesses), and living with chronic pain. Other causes mentioned by the patients included financial problems because of unemployment, dependency on financial assistance programs, and health care costs (especially the costs associated with having multiple illnesses); and dealing with loss including the death of their children, parents, and close friends and the manifestations of the bereavement including their own mortality, compounded by their poor health. The causes of depression reported by patients could help explain part of the difficulty treating depression in primary care, some of which have not been reported before in the literature. For example, causes like physical health including diseases with no remission, financial difficulties, unemployment, and bereavement are not necessarily ideal for conventional pharmaceutical treatments, necessitating different approaches depending on the patient’s experience.

In contrast to patients identifying many different causes of their depression, self-reported descriptions of symptoms were actually quite consistent. Most of the symptoms centered on emotional responses to trauma resembling the clinical symptoms for depression (e.g., hopelessness, sadness), along with physical symptoms of fatigue, and physical pain. Since depression is measured using validated, survey-type instruments (e.g., PHQ-9, Hamilton Depression Scale), patients are not typically afforded the opportunity to share any additional symptoms outside of the clinical symptoms such as chronic pain, problems with diet and digestion, and defeated feelings around having chronic illnesses.
**Perceived Relationship between Depression and Chronic Illness**

One of the aims of the qualitative interviews was to describe how patients view the relationship between depression and chronic illness, an unexplored aspect of the patient narrative in the existing literature (Bayliss, 2012). When asked about the *causes* of depression, patients described their overall health status as well as specific illnesses as substantial contributors, including feelings of distress particularly around diagnosis, feelings of hopelessness particularly around prognosis, high levels of chronic stress when dealing with treatment regimens and the various appointments with healthcare providers and healthcare costs common for complex patients. For example, some chronic conditions can be felt as a burden with no hope for remission, and though patients are diligent about appointments and treatment plans, general depressive symptoms are felt as a result of constantly being ill, keeping patient’s attitudes down.

The relationship between depression and chronic illness was also noted by patients while discussing their *symptoms* of depression. One of the most substantial ways patients experienced the bi-directional relationship between their depression and illness is the effects of a symptom like sadness has on their social functioning. Social functioning and engagement are crucial for both the prevention and management of depression symptoms and chronic illness. For example, literature around social functioning shows the importance of social relationships and interactions as crucial to improving depressive symptoms (Cruwys, et al., 2014; Gleibs, et al., 2011), and conversely the relationship between social isolation (i.e., loneliness) and depression (Cacioppo, Hawkley, & Thisted, 2010; Trivedi, Morris, Pan, Grannemann, & John Rush, 2005). Patients shared their desires to be alone as not to be a burden on loved ones, socializing being reserved for healthcare visits, not wanting to be around others due to their chronic mood swings.

Patients also experienced the bi-directional relationship in how their chronic illnesses (e.g., pain, physical complications from diabetes) physical functioning that included daily tasks, exercise and activity, and household chores – with those limitations causing frustration, and depression. These feelings are further exacerbated by the loss of autonomy caused by having
physical illnesses, forcing dependence on others, and inability to work for wages, all adding to the feelings of depression. Patients’ experience around social and physical functioning contributed to a diminished quality of life and self-value. Living with multiple illnesses impacts the daily functions for patients associated with normalcy, leading to a low level of interest in tasks, or sometimes a fear felt by the risks associated with daily functions that could potentially compound their chronic illnesses (Fortin, Dubois, Hudon, Soubhi, & Almirall, 2007; Fortin, et al., 2004).

Illness Priority and Competing Demands

An important theme from the interviews concerned how patients, given their illness complexity, prioritize their illnesses in terms of clinical importance (agenda setting) and treatment. Though I hypothesized patients would want to prioritize their new episode of depression, the patients interviewed for this study put importance on their physical ailments. This could be directed by the expectation of treating physical conditions only in primary care, and mental health detection and treatment being less emphasized (Kravitz & Ford, 2008; Nutting, et al., 2002; Nutting, et al., 2000), as well as patients not reporting depression symptoms to their primary care provider (Bell, et al., 2011). Problems with weight, chronic pain, hypertension, and diabetes complications were among those illnesses mentioned as priorities for treatment in spite of being aware of depression. When it comes to treatment priorities, patients overwhelming preferred focusing on their chronic conditions explaining that having more control over their chronic illnesses would improve their mental health by increasing their autonomy, activity levels, social interactions, having to live with less pain, and having less worry about illness prognosis.

An important aspect of this research was to elucidate the role of competing demands for patients who are seeking or receiving care for their depression. The three main themes identified concerning competing demands for the patients interviewed were the treatment and control of other competing illnesses, family responsibilities including care of sick individuals and parental responsibilities, and economic demands including having to prioritize medications because of costs, feeling the costs of depression care being too much to take on, and being on a fixed
income. There is some evidence that because complex patients have several conditions needing management simultaneously, those illnesses compete with one another and affect the quality of care (Ani, et al., 2009; Jaen, et al., 1994; Stange, et al., 1994; Vogeli, et al., 2007; Vyas & Sambamoorthi, 2011), including mental health care (Klinkman, 1997; Rost, et al., 2000). Three studies since 2005 have concluded that depression care in primary care settings is not affected by the competing demands due to multiple chronic conditions (Ani, et al., 2009; Harman, Edlund, Fortney, & Kallas, 2005; Vyas & Sambamoorthi, 2011). Though the quantitative analyses support this assertion, the findings from the interviews show a strong connection between patients’ coexisting illnesses and either seeking treatment for, or managing their depression. Patients mentioned trying to live with chronic pain, problems with weight, along with the burdens felt from being a complex patient. One methodological reason for the conflicting findings could be that this dissertation used semi-structured interviews to gauge the influence of competing demands on depression as opposed to a more rigid survey approach without much latitude for context found in the studies mentioned earlier.

Additionally, the interviews offer some challenges to the potential assumptions of depression interventions in primary care settings that may see depression as a separate condition from patients’ chronic illnesses and need isolated treatment. It can be theorized that the patients interviewed for this study see their depression as the result of many of the difficulties associated with illness complexity. If this is true, then interventions aimed at improving symptoms of depression should focus on treatment adherence and management of chronic illness and dialogue around the social implications of being a complex patient, not necessarily recommending therapy or medication for depression specifically. By controlling illnesses enough to increase social activity and patient autonomy, decreasing pain and worry about prognosis, as well as partnerships with professionals such as social workers could have a potential impact on symptoms of depression for primary care patients.
Assessing Methodology

The strength of this dissertation was the use of mixed methodology, particularly given that the quantitative portion of this research did not yield significant findings. Interviews provided a compelling forum for patients to offer a narrative of their lived experience with depression. The prevalence of depression in primary care and the difficulties with adequately treating depression suggest the need for a broader, more contextual approach than the limited understanding and objectivity of quantitative research alone. Understanding how depression manifests differently in populations, how it is experienced and described, and how it impacts the everyday lives of individuals necessitates additional explanation, and combination of approaches to increase the depth of understanding of a very complex health condition (Wisdom, Cavaleri, Onwuegbuzie, & Green, 2012).

Interestingly, though the HLM showed no relationship between chronic illness severity and change in depression, patients described a strong relationship between their illnesses and their symptoms of depression, including that their illnesses hindered their seeking mental health treatment. The addition of semi-structured interviews offered important perspectives and a rich context of the lived experience of depression and compelling discrepancies between the quantitative and qualitative results that also raised important, additional questions for future study.

Conclusion

Providing quality depression treatment in primary care settings for complex patients is challenging and though the severity of chronic illnesses competing with depression could impede depression symptom improvement. Though this study was unable to identify a relationship between chronic illness severity and depression symptom improvement, additional efforts are needed to improve the understanding of chronic illness burden on depression outcomes. Given this, interventions aimed at improving mental health care in these settings is imperative and must
include support and training for primary care providers to deal with any ambivalence about discussing and treating mental health illnesses. Additionally, we lack studies of potential confounders of depression symptom improvement; qualitative findings suggest that factors such as health status, economic, socio-cultural and environmental influences could also impact depression – but they are not usually included in our measures.

Another important aim for this dissertation was to improve understanding of how patients, in their own words, experience, describe and impact their daily living, and how patients prioritize their treatment. Findings suggest that, although competing illnesses did not impact depression change in quantitative models, patients reported dealing with a multitude of problems that complicate and sometimes adversely contribute to their health. Though the importance of effective communication between primary care providers and patients has shown to be crucial for patients to have an accurate understanding about depression as well as treatment expectations (Malpass, et al., 2009; Stanners, Barton, Shakib, & Winefield, 2014), I propose that there is information beneficial for providers from patients sharing their narratives. The interviews offered patients the chance to share their narrative to better understand their lived experience with depression and coexisting illness. This affords the opportunity to record the descriptions correctly and understand the key antecedents and consequences of the course of illness (Kleinman, 1988). A patient is more than a “malady” but a person with a complex life, competing demands influencing decision making, and illness behavior, and knowing this can only deepen a primary care provider’s understanding of their patient’s experience with illness. The clinical encounter can only benefit from dialogue that contextualizes the patient’s narrative, and from being encouraged to share biographical information.

Though the impact of learning about the patient’s lived experience with multiple illnesses during the clinical encounter has been studied previously (Barry, Stevenson, Britten, Barber, & Bradley, 2001; Coventry, Dickens, & Todd, 2014), further research is needed to better measure the quality of dialogue during the clinical encounter, testing patient satisfaction with visits where
their narrative is shared, and the potential impact sharing their narrative with providers has on their depressive symptoms and other chronic illnesses. In addition, although this study did not show a statistical relationship between chronic illness severity and change in depression, qualitative findings did suggest that illness severity has some influence on depression symptoms which should be further tested using methods that measure illness severity differently than the CIRS, including a self-reported illness severity instrument.

Future research should use different methods to measure coexisting illness including self-reported measurements as opposed to medical chart reviews used for this study. For example, this dissertation study would have potentially benefitted from using self-reported illness severity ratings which could give a more current and accurate understanding of just how a patient feels and measures their illnesses compared to a medical chart, which though is more thorough, it still relies on socially constructed definitions of illness. Also, findings from this research revealed a need for additional research on the impact of the differences in how patients with depression describe the causes of their symptoms. The interview data revealed a variety of causes of depressive symptoms and it could be that how patients view these causes, impacts their treatment priority and response. For example, patients who see their depression as almost normal reaction to having multiple chronic illnesses are prioritizing, and could benefit from, treatment on better controlling and improving their chronic conditions than to their depression symptoms, including but not limited to, anti-depressants. What this suggests is a possible over-medicalizing of the emotional responses to illness complexity and life struggles, especially among financially-and medically-indigent populations.

**Limitations**

Several limitations to this study should be recognized. First, the quantitative analyses were done using secondary data from a nearly completed RCT, the sample size for the project was small and only included patients using Denver Health and Hospitals for their health care,
therefore compromising generalizability, not all of the 168 patients completed depression scores for all four time points. Also, no data was collected concerning the patients approached to participate in the original RCT. Additional limitations for both the quantitative and qualitative analyses are described below.

**Limitations of the Quantitative Analyses**

There were several limitations to the quantitative phase that should be noted. First, there was a lack of statistical power due to small numbers of patients in the original RCT. Patients included in this study were English-speakers and had to have access to a telephone and a physical address. This study only examined linear changes in depression over a relatively short time period, there is a relatively small sample size, and depression was measured using self-report. Additionally, CIRS was only measured once at baseline, which did not afford the opportunity to view trajectories of illness severity at various time points. The depression measures were self-reported and therefore subject to recall bias. The reliability of the medical record abstractions may have also limited the findings, though steps were taken to ensure fidelity of the CIRS scoring. Also, the analyses did not control for demographic and social characteristics other than gender.

**Limitations of the Qualitative Analyses**

Findings from the qualitative data are limited to the clinical settings from which patients were recruited, and less applicable to health care settings with different funding levels and patient demographics. The recruitment strategy or individual primary care patients was limited to those with moderate depression and competing physical illness, which does not represent all primary care patients receiving their care in community clinics. Also, because of difficulty contacting patients and getting consent to complete an interview, selection of the patients to be interviewed could not be as rigorous, therefore not having the kind of variability across patients that was proposed. Interviews were only done with a limited sample and those patients who spoke English. Interviews were short, and only represent a snapshot of the patient’s experience with their illnesses.
Dissemination of Results

In addition to serving as the basis for my dissertation and doctoral degree, I will submit sections of this study to peer-reviewed academic journals and present my findings at local and national meetings and conferences. Some of the journals I anticipate submitting to include the Journal of Behavioral Medicine, Annals of Family Medicine, and the Journal of Primary Care & Community Health as all three of these journals publish articles associated with my topic. I also anticipate presenting my findings at the Society of Behavioral Medicine national conference in 2014 as well as the North American Primary Care Research Group national conference. Additionally, the results will be presented to Denver Health given the participants were recruited from their community health centers, and to research colleagues and medical students in the Colorado area.
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APPENDIX
A. Glossary of Terms

Use of terms in this report follow definitions from various peer-reviewed articles, government and organization reports, and textbooks and were adopted to communicate to a broad audience about mental illness, primary care, and specific populations. Citations refer to the source of term’s definition.

Adherence (medication/treatment)
The extent to which a person’s behavior is consistent with health care recommendations. (Haynes, 1979)

Allostatsis/Allostatic Load
Refers to an imbalance in systems that promote adaption, such as the autonomic nervous system and hypothalamo-pituitary-adrenal axis, to stress usually as a result of overexposure to chronic or repeated stress which can cause physical damage (often manifesting as physical illness) or promote pathology. (McEwen, 1998)

Chronic Illness
Chronic diseases are diseases of long duration and generally slow progression. Chronic diseases, such as heart disease, stroke, cancer, chronic respiratory diseases and diabetes, are by far the leading cause of mortality in the world, representing 63% of all deaths. (World Health Organization, 2013)

Colorado Indigent Care Plan
Provides funding to clinics and hospitals so that medical services can be provided at a discount to Colorado residents that meet the eligibility requirements. (State of Colorado)

Competing Demands
Factors considered by either the patient or provider that compete with each other for time on the agenda of the medical office visit, or potentially impede treatment adherence or prioritizing. These demands can include but are not limited to competing illness, values, cost, and reason for visit. (Stange, et al., 1994)

Complex Patient
Patients with multiple chronic conditions occurring simultaneously often resulting in decreased quality of life, longer hospital stays, psychological distress, and higher mortality. (Fortin, Soubhi, et al., 2007)

Cumulative Illness Rating Scale (CIRS)
A tool used to measure morbidity that considers all medical problems encountered in primary
care and allows for severity to be assessed based on a diagnostic manual. (Hudon, Fortin, & Vanasse, 2005)

**Depression** A common mental disorder, characterized by sadness, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, feelings of tiredness and poor concentration. (World Health Organization, 2001)

**Diagnostic and Statistical Manual of Mental Disorders (DSM)**
The standard classification of mental disorders used by mental health professionals in the United States. (American Psychiatric Association, 2000; American Psychiatric Association (APA), 2012)

**Health Disparity**
Differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States. (National Institutes of Health (NIH), 2000)

**Hierarchical Linear Modeling**
Statistical modeling for social research that allows for individuals in a study to be classified or arranged in groups which themselves have qualities that influence the study, developed to allow for the study of relationships at any level in a single analysis, while not ignoring the variability associated with each level of the hierarchy. (Scientific Software International (SSI), 2013)

**International Classification of Diseases (ICD)**
The standard diagnostic tool for epidemiology, health management and clinical purposes and is used to classify diseases and other health problems. (World Health Organization (WHO), 2013)

**Medicaid**
A health and medical services program for individuals and families with low incomes and few resources. (2013)

**Medically Indigent**
The class of people who cannot afford necessary medical care from their own resources or from health insurance coverage, if any, including those individuals or families with medical expenses that exceed that of their income and assets. (Bovbjerg & Kopit, 1986)

**Minority (race/ethnicity)**
Includes African Americans, Hispanics, Asians, Pacific Islanders, American Indians and any other race/ethnicity underrepresented usually resulting in economic and social implications. (Pollard & O'Hare, 1999)

**Moderator (analysis)**
Factors that specify for whom and under what conditions a treatment works, helping to clarify the best choice for inclusion and exclusion criteria or the best choice of stratification, providing valuable information to inform future studies and interventions. These include sex,
age, ethnicity, socioeconomic status, initial severity, genotype, biomarkers, or the subtype of the disorder under investigation. (Kraemer, Frank, & Kupfer, 2006)

**Motivational Interviewing**
An evidence-based practice that focuses on exploring and resolving ambivalence and centers on motivational processes within the individual that facilitate change. (Emmons & Rollnick, 2001)

**Patient Health Questionnaire-2 and 9**
Instruments for making criteria-based diagnoses of depressive and other mental disorders commonly encountered in primary care. (Kroenke, et al., 2001)

**Primary Care**
Primary care is that care provided by physicians specifically trained for and skilled in comprehensive first contact and continuing care for persons with any undiagnosed sign, symptom, or health concern (the "undifferentiated" patient) not limited by problem origin (biological, behavioral, or social), organ system, or diagnosis. It includes health promotion, disease prevention, health maintenance, counseling, patient education, diagnosis and treatment of acute and chronic illnesses in a variety of health care settings (e.g., office, inpatient, critical care, long-term care, home care, day care, etc.) and is performed and managed by a personal physician often collaborating with other health professionals, and utilizing consultation or referral as appropriate. (American Academy of Family Physicians, 2013)

**Primary Care Provider**
A primary care physician is a generalist physician who provides definitive care to the undifferentiated patient at the point of first contact and takes continuing responsibility for providing the patient's care. Such a physician must be specifically trained to provide primary care services. Primary care physicians devote the majority of their practice to providing primary care services to a defined population of patients. The style of primary care practice is such that the personal primary care physician serves as the entry point for substantially all of the patient's medical and health care needs - not limited by problem origin, organ system, or diagnosis. Primary care physicians are advocates for the patient in coordinating the use of the entire health care system to benefit the patient. (American Academy of Family Physicians, 2013)

**Self-efficacy**
Self-judgment of one’s ability to perform a task within a specific domain, influencing the factors that predict motivation. (Bandura, 1977)

**Socially/Economically Disadvantaged Populations**
Individuals or groups including but not limited to those living in poverty, minority ethnic groups, mentally and physically disabled, older adults, and individuals dealing with addictions that are marginalized and disenfranchised socially and politically. (Allen, 1969)
**Socioeconomic status (SES)**
Commonly conceptualized as the social standing or class of an individual or group; often measured as a combination of education, income, and occupation. (American Psychological Association (APA), 2013)
B. Patient Health Questionnaire-2

The Patient Health Questionnaire-2 (PHQ-2)

<table>
<thead>
<tr>
<th>Over the past 2 weeks, how often have you been bothered by any of the following problems?</th>
<th>Not At all</th>
<th>Several Days</th>
<th>More Than Half the Days</th>
<th>Nearly Every Day</th>
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</thead>
<tbody>
<tr>
<td>1. Little interest or pleasure in doing things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>2. Feeling down, depressed or hopeless</td>
<td>0</td>
<td>1</td>
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</table>
C. Patient Health Questionnaire-9

<table>
<thead>
<tr>
<th>QUESTION</th>
<th>Score</th>
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<th>Score</th>
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<tbody>
<tr>
<td>1. Little interest or pleasure in doing things</td>
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<tr>
<td>2. Feeling down, depressed, or hopeless</td>
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<td>3. Trouble falling or staying asleep, or sleeping too much</td>
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<td>4. Feeling tired or having little energy</td>
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<td>5. Poor appetite or overeating</td>
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<td>6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down</td>
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<td>7. Trouble concentrating on things, such as reading the newspaper or watching television</td>
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<td>8. Moving or speaking so slowly that other people could have noticed, or the opposite—being so fidgety or restless that you have been moving around a lot more than usual</td>
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<tr>
<td>9. Thoughts that you would be better off dead, or of hurting yourself in some way</td>
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<td>10. If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?</td>
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</table>

(add columns: + + + TOTAL:)

(Hospital professional: For interpretation of TOTAL, please refer to accompanying scoring card.)
D. Demographic Variables Questionnaire

A. Do you consider yourself to be Hispanic or Latino?
   A. YES
   B. NO
   C. UNSURE
   D. PREFER NOT TO ANSWER

If respondent is uncertain, read the following prompt: Where do your ancestors come from? If respondent answers yes to any of the following, code as Hispanic.

   A. PUERTO RICO
   B. CUBA
   C. DOMINICAN REPUBLIC (AMERICAN DOMINICAN)
   D. MEXICO (MEXICAN AMERICAN)
   E. CENTRAL OR SOUTH AMERICAN COUNTRY
   F. OTHER LATIN AMERICAN COUNTRY
   G. OTHER HISPANIC OR LATINO CULTURE (SUCH AS SPAIN)
   H. DON’T KNOW
   I. PREFER NOT TO ANSWER

B. What race do you consider yourself to be? Please select one or more, and choose all that apply.
   A. AMERICAN INDIAN OR ALASKAN NATIVE
   B. ASIAN
   C. BLACK OR AFRICAN AMERICAN
   D. NATIVE HAWAIIAN OR PACIFIC ISLANDER
   E. WHITE
   F. OTHER
   G. DON’T KNOW
   H. PREFER NOT TO ANSWER

C. Are you:
   A. MARRIED
   B. DIVORCED
   C. WIDOWED
   D. SEPARATED
   E. NEVER MARRIED
   F. MEMBER OF AN UNMARRIED COUPLE
   G. PREFER NOT TO ANSWER

D. What is the highest grade or year of school you completed? If respondent is uncertain, read the following prompt:
   A. NEVER ATTENDED SCHOOL or ONLY KINDERGARTEN
   B. GRADES 1-8 (Elementary)
   C. GRADES 9-11 (Some high school)
   D. GRADE 12 or GED (High school graduate)
   E. COLLEGE 1 YEAR TO 3 YEARS (Some college or technical school)
E. Are you currently:
   A. EMPLOYED FOR WAGES AT A BUSINESS THAT YOU DO NOT OWN
   B. SELF-EMPLOYED/BUSSINES OWNER
   C. OUT OF WORK FOR MORE THAN A YEAR
   D. OUT OF WORK FOR LESS THAN A YEAR
   E. A HOMEMAKER
   F. A STUDENT
   G. RETIRED
   H. UNABLE TO WORK DUE TO MENTAL OR PHYSICAL HEALTH PROBLEMS
   I. UNABLE TO WORK DUE TO FAMILY OBLIGATIONS SUCH AS
      CHILDRearing OR CARE OF AGING PARENTS
   J. PREFER NOT TO ANSWER

F. Is the annual income from all sources for this household:
   A. LESS THAN $10,000
   B. LESS THAN $15,000
   C. LESS THAN $20,000
   D. LESS THAN $25,000
   E. LESS THAN $35,000
   F. LESS THAN $50,000
   G. LESS THAN $75,000
   H. $75,000 OR MORE
   I. DON’T KNOW
   J. PREFER NOT TO ANSWER

G. How many people, including yourself, depend on this income, even if they do not live with you?
   A. 1
   B. 2
   C. 3
   D. 4
   E. 5
   F. 6 or more

H. Are you Homeless, residing in a shelter or transitional housing program, or staying with friends or
   extended family?
   A. HOMELESS
   B. RESIDING IN A SHELTER
   C. RESIDING IN A TRANSITIONAL HOUSING PROGRAM
   D. STAYING WITH FRIENDS OR EXTENDED FAMILY (IF YES, PROCEED TO
      QUESTION 9. IF NO, SKIP TO QUESTION 10).

I. How many people currently live in your home?
   A. 1
   B. 2
   C. 3
D. 4
E. 5
F. 6 or more

J. If you have health insurance, does your health plan help cover the cost of prescription drugs?
   A. YES
   B. NO
   C. DON’T KNOW
   D. PREFER NOT TO ANSWER

K. Was there a time in the past 12 months when you needed to see a doctor but couldn’t?
   A. YES (IF YES, ASK FOR THE SPECIFIC REASON)
   B. NO
   C. DON’T KNOW
   D. PREFER NOT TO ANSWER

L. Was there a time in the past 12 months when you needed to fill a prescription but couldn’t fill it?
   A. YES (IF YES, ASK FOR THE SPECIFIC REASON)
   B. NO
   C. DON’T KNOW
   D. PREFER NOT TO ANSWER
E. Cumulative Illness Rating Scale (CIRS)

CIRS RATING SHEET

PI: Robert Keeley, MD MPH

Patient ID: ____________  Age: ___  Date Range: ________________  # 1 of 168

RATING STRATEGY
0- No problem
1- Current mild problem or past significant problem
2- Moderate disability or morbidity/requires first line therapy
3- Severe/constant significant disability/ uncontrollable chronic problems
4- Extremely severe/immediate treatment required/ end organ failure/ severe impairment in function

<table>
<thead>
<tr>
<th>Rating</th>
<th>Heart</th>
<th>Vascular</th>
<th>Hematopoietic</th>
<th>Respiratory</th>
<th>Eyes, Ears, Nose, Throat and Larynx</th>
<th>Upper GI</th>
<th>Lower GI</th>
<th>Liver</th>
<th>Renal</th>
<th>Genitourinary</th>
<th>Musculoskeletal/Integument</th>
<th>Neurological</th>
<th>Endocrine/Metabolic and Breast</th>
<th>Psychiatric Illness</th>
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Total: ________  =  ____________

GRAND TOTAL

Baseline BMI: _______  ☐ On Hypertension Med? If so, baseline BP: _______

Smoking Status:  Never  Former  Current

Initials: _______  Date: _______

Created by: Matthew Engel, MPH

Version 3, last modified: 5/03/13
F. Qualitative Interview Guide

Introduction script to be read after consent from the patient is given:

Thank you very much for taking the time to talk with me. The purpose of this interview is to better understand how you communicate with your doctor about your illnesses, particularly feelings of stress and depression. When I use the term doctor, I mean whoever handles most of your health care. Also I would like to ask you some questions about what other problems might get in the way of your treating your illnesses. I will tape record our interview and to ensure confidentiality, your name will not be on the tape. Is this okay with you? I know I mentioned this already, but I want to remind you that you can stop this interview at any time and you do not need to answer every question. To get started, I am going to ask you a couple of background questions:

Introductory

What is your age?

How long you been going to Denver Heath for care?

How long have you been seeing your current doctor?

I would like to know more about your experience as a patient here at Denver Health.

4. Can you tell me about your relationship with your doctor?

   PROBE: What do you like best?

   PROBE: What would you like to improve?

6. What illnesses you are currently dealing with?

7. Can you share with me which of those illnesses you mentioned worries you the most?

   6A. Why that illness?

   6B. What is your biggest worry?

8. How does having more than one illness impact your everyday life?

   PROBE: Does it make it more difficult?

   8A. Can you describe some ways having more than illness affects your mental health?
Patient Experience with Depression

The purpose of the study you participated in was to help patients dealing with depressive symptoms. One of the purposes of this interview is to better understand how patients understand depression and how depression impacts a patient.

11. Earlier when I asked about you about your current illnesses

EITHER:

a. you didn’t mention depression, can you tell me why?

b. you mentioned depression, Given your experience how does your depression affect your physical illnesses?

12. Describe to me what depression means to you? How do you recognize it in yourself?

12A. How would you recognize it in people you know?

13. Originally to be in the study, you had to show signs of depression. Looking back, why do you think you were identified as having depression?

[IF ANSWERED, “I WAS DEPRESSED]

13A. How did you know?

13B. Where you surprised that you identified as having depression?

14. Had you been diagnosed with depression before?

[IF YES] Was this time different?

[IF YES OR NO] What did this new diagnosis mean to you?

15. You listed (several) illnesses previously, how do you and your doctor determine which is most important to treat?

16. Have you ever talked to your doctor about depression?

[IF YES] A. Who brings it up – you or your doctor?

B. Could you describe with as much detail as you remember a time when you talked with your doctor about your depression.

[IF NO] Why don’t think it was every talked about?

17. Earlier I asked you about which illnesses worried you. How did knowing you had signs of depression change what you worry about?

18. Again going back to those illnesses you mentioned that most worry you, do you think those illnesses affect your overall health more than depression?

19. How do you feel about your doctor here at Denver Health treating your depression?
Depression impacts and lived experience descriptions

19. Tell me in what ways depression has affected your daily activities.

20. How about some ways being depressed has affected your health directly?

   PROBE: How often does it happen?
   PROBE: Can you remember the last time it happened?

21. Please describe an example of a time when your mood might have affected your physical health?

22. What barriers get in the way of you feeling better?

   PROBE: It could be during the visit or something experience personally or socially.

22A. Can you describe a specific time when one of those barriers kept you from doing something about your health?

23. Finally, between your physical illnesses and your mood (depression), which if treated would improve your overall health most?
E. Diagram of the relationships between levels of coding in the qualitative analysis