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College of Health Sciences

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Walden University
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Abstract

Experiences and Perceptions of Patients With Chronic Diseases Regarding Chronic

Disease Management

by

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MA, Walden University, 2008

BS, Brooklyn College, 2006

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

In spite of the current shift from acute to chronic care models, little is known about how patients perceive the changes to service delivery described by chronic care models. The purpose of this study was to examine the experiences and perceptions of patients with chronic diseases to fill the gap of lack of knowledge about the impact of these changes in chronic disease management (CDM). For this purpose, a mixed methods approach was used. The constructivist paradigm provided the conceptual framework for this study. A purposeful sampling strategy was used to identify 200 adults with at least one chronic disease. The Patient Assessment of Chronic Illness Care (PACIC) instrument was used to assess the perception of CDM for the quantitative component, and 11 individual interviews were performed for the qualitative component. Data were analyzed using inferential statistics for quantitative data and thematic analysis for qualitative data. The dependent variables were PACIC scores. The independent variables were characteristics of the sample and of the chronic conditions of the participants (e.g., type, number, etc.), which were recorded additionally to the PACIC survey. According to the quantitative results, educational level and race were found to significantly predict the perception of CDM. Importance of medication and religion beliefs were the most significant themes emerged from the qualitative interviews. Public health policy makers and health teams related to CDM can benefit from this study's results. By increasing their focus on the empowerment of the role of families, support groups, and effective medications in CDM, these practitioners can improve the quality of life of this population group and thus promote positive social change.

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Dedication

I dedicate this dissertation to my family.

Acknowledgments

I would like to acknowledge the help of my dissertation committee, family members, and friends who have assisted me reach this point in my academic career.

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Chapter 1: Introduction to the Study

Introduction

Although the prevalence of chronic diseases is increasing worldwide, there is little known on how patients perceive and qualitatively evaluate chronic diseases management (CDM). In United States, chronic diseases affect the life of more than 90 million individuals (Mathers & Loncar, 2006); therefore, understanding in depth the perceived type of help that these patients get from their health care team is important to promote their adjustment to the distressing illness experience and eventually to improve the management of their diseases. The purpose of this study was to examine the experiences and perceptions of patients with chronic diseases regarding CDM. Details on the introduction of the topic are provided in the first chapter of the dissertation. I describe the background of the study, the research problem, the nature of the study, the research questions, the aim, and the significance of the study.

Background of the Study

The prevalence of chronic diseases, such as heart disease, stroke, cancer, chronic respiratory diseases, and diabetes is increasing worldwide. Chronic diseases may be the leading cause of deaths and disability in 2030 (Mathers & Loncar, 2006). As far as United States is concerned, chronic diseases affect the quality of life of 90 million individuals (Mathers & Loncar, 2006). Mental disorders and communicable diseases such as HIV/AIDS are managed as chronic diseases. Chronic diseases place challenging demands not on only patients but also on their families, caregivers, and health and social services (Kavanagh, 2010). Chronic diseases demand complex care models, such as the

chronic care model (CCM; Wagner, 1998), requiring collaboration between health teams and caregivers, which traditionally have been disconnected and oriented towards acute care (Kavanagh, 2010). CCMs must be aimed at creating empowered and informed chronic diseases patients as well as proactive health or/and social care teams (Wilson, 2001).

Although researchers have encouraged health care providers to coordinate and improve health services as well as to promote patients' self-management (Bodenheimer, Wagner, & Gumbach, 2002; Wagner, 1998), there is little known on how patients perceive the changes to service delivery envisaged by chronic care models (Wilson, Brooks, Procter, & Kendall, 2012). Understanding the perceived type of help that these patients get from their health care team is important to promote their adjustment to the distressing illness experience. The following overview covers the state of understanding of CDM, and introduces an approach to better comprehend the experiences and perceptions of patients with chronic diseases regarding CDM. A more thorough review is found in Chapter 2.

The Problem Statement

There has been a shift from acute to chronic care models. Globally, a range of models has emerged to deliver CDM and providing a new focus on the CDM process where the patient is recognized as an active participant in care (Wilson, 2001). These models have been pilot-tested in several countries, such as the United States, Canada, Ireland, and United Kingdom (Wilson et al., 2012). Researchers have indicated patient and caregiver preference for these models compared to previous service settings (Boaden

et al., 2006, Sargent et al., 2007). Previous scholars have suggested that patients appreciated the psychosocial skills and availability and ease of access to the health team working within CDM (Wilson et al., 2012). Barriers to the achievement of these outcomes may be related to the lack of effective consultation and communicative skills.

Although chronic diseases need to be studied from a combination of perspectives, using both qualitative and quantitative methods (Casebeer & Verhoef, 1997), there is a lack of studies on the experiences and perceptions of patients with chronic diseases regarding CDM using a mixed-methods research approach. Understanding the perceived type of help that these patients get from their health care team is important to promote their adjustment to the illness experience. In this study, I attempted to fill the aforementioned gap by focusing quantitatively and qualitatively on the patient views and perceptions of needs and priorities regarding CDM.

Conceptual Framework

Patients' experiences and perceptions regarding CDM were explored with the use of a qualitative case study approach. This approach included the investigation of a phenomenon (the perceived CDM) with a variety of lenses which allows for multiple facets of the phenomenon to be revealed and understood (Baxter & Jack, 2008). The constructivist paradigm provided the framework for this study. A constructivist "recognizes the importance of the subjective human creation of meaning, but doesn't reject outright some notion of objectivity. Pluralism, not relativism, is stressed with focus on the circular dynamic tension of subject and object" (Miller & Crabtree, 1999, p. 10). This qualitative approach was a descriptive case study, in which patients'

experiences regarding CDM and the real-life context in which they occurred were described and analyzed (Baxter & Jack, 2008). The objective ratings by chronic disease patients regarding the assessment of care for chronic conditions (quantitative section of the study) were used for the best possible selection of the participants for the qualitative component of the study.

Nature of the Study

Combined method approaches are used to connect the study objectives and methodologies in the context of a single study for accessing a more comprehensive range of information and experience (Casebeer & Verhoef, 1997). The use of different research methods within a single study can provide a richer and deeper understanding of the area under investigation than would otherwise be possible (Corner, 1991). Consequently, the combined quantitative and qualitative data which were obtained may lead to a deeper comprehension and analysis of perceived CDM.

The nature of this study was a mixed-method study with a quantitative focus. Qualitative research was used to understand how patients perceived CDM; I analyzed the patients' own words and perspectives. On the other hand, objective ratings of care for chronic diseases with the use of the instrument (Patient Assessment of Chronic Illness Care [PACIC] survey instrument) were used to elucidate the emerged themes. I used the quantitative analysis to summarize the information obtained during the research process.

Research Questions and Objectives of the Study

Research questions contribute to determining the type of research study that will be conducted. In this study, I answered the following research questions:

1. Based on objective ratings by chronic diseases patients, what is the assessment of care for chronic conditions?
2. For patients with chronic diseases, what themes emerge in their reports regarding perceived CDM and thus their quality of life?

The main purpose of this study was to investigate and comprehend, quantitatively and qualitatively, the perceived CDM of patients with various chronic diseases. Also, I wished to produce new knowledge on CDM in order to enable health professionals to better understand and help patients with chronic diseases. Consequently, there was no null or alternative hypothesis because I focused on discovering the meaning of patients' ratings and words.

The PACIC survey was used in order to assess the care of chronic conditions (quantitative component of the study). This survey will be presented in Chapter 3 with more details. The dependent variables of the quantitative study were the five subscales of the questionnaire, which are based on the key components of the CCM: patient activation, delivery system design/decision support, goal setting, problem-solving/contextual counseling, and follow-up/coordination. The independent variables were gender, age, education level, race/ethnicity, marital status, insurance status, types and number of chronic conditions, and years lived with these diseases. Additionally, an interview guide with open-ended questions with a wide coverage of interest, including all the aforementioned variables, was used in order to understand perceived CDM (qualitative component of the study).

Definitions

Acute care model: Immediate management of symptoms or complications related to chronic diseases, mostly in a hospital (Wagner, 1998). This kind of care is not meant to continue for long periods of time.

Assessment of care for chronic conditions: This assessment is usually based on objectives ratings by patients with chronic diseases in order to learn about the type of assistance that a patient receives from his/her health care team.

The chronic care model (CCM): This model is used to identify the essential elements (community, the health system, self-management support, delivery system design, decision support, and clinical information systems) of a health care system that encourage high-quality chronic disease care (Improving Chronic Illness Care [ICIC], 2012).

Chronic diseases: Chronic diseases are diseases of long duration and generally slow progression (The World Health Organization [WHO], 2012). Chronic diseases, such as heart disease, stroke, cancer, chronic respiratory diseases and diabetes, are the leading cause of mortality in the world, representing 63% of all deaths (WHO, 2012).

Chronic disease management (CDM): CDM is a clinical management process of care. It spans the continuum of care from primary prevention to ongoing long-term maintenance for individuals with chronic health conditions or disease (Rand, Vilis, Dort, & White, 2007).

Health team working within CDM: This team includes health professionals who are involved in the management of chronic diseases. Doctors, nurses, physician's assistants, and psychologists are usually members of this team.

PACIC survey instrument: The PACIC is used to measure actions or qualities of care congruent with the CCM that patients report they have experienced in the delivery system (author, year). The survey includes 20 items, and it is sufficiently brief to use in many settings (ICIC, 2012).

Perceived CDM: This concept describes the thoughts, emotions, feelings, and possible reactions of patients with chronic diseases, as far as CDM is concerned.

Self-management: The decisions and behaviors that patients with chronic illness engage in that affect their health (ICIC, 2012).

Assumptions of the Study

In this study, I focused on analyzing the complex needs of patients with chronic diseases. Patients with these types of diseases and their families have different needs from other patients and these needs are not likely to be met by an acute care culture, which is promoted by the majority of health care systems. In this study, I assumed that a more patient-centered health care system, focusing on the individual needs of each patient with chronic disease(s) as well as on the perceived behavior of health care providers, would be beneficial for both patients and families. For this purpose, an in-depth comprehension of patients' perceptions about CDM is essential.

Limitations of the Study

The research study had its own scope and limitations. I examined the perceived CDM within the United States only, using a convenience study sample recruited from one church of Chicago and surrounding communities. Therefore, generalization to populations with chronic diseases outside of the United States, where health system and socioeconomic factors may differ, should be made with caution. Additionally, certain information was retrieved from patients' questionnaires and narratives and is, therefore, subject to recall bias. Finally, some researchers, especially with a positivist background, raise concerns about what kind of research questions are addressed using qualitative analysis, while there is a controversy about whether there are adequate methodological standards in order to achieve the best possible validity and reliability of qualitative data (Poses & Isen, 1998).: In order to achieve the maximum validity and reliability of the analyzed patterns/themes, all coding reports were read independently by myself and my dissertation supervisor (V.M.) for discussing similarities and differences in interpretation of the qualitative data.

Scope and Delimitations of the Study

The goal of this study was to provide better care to patients with chronic diseases by focusing on the way health care is delivered to these patients. I revealed the perceived behavior of the health team and care system in general and I identified barriers and inappropriate practices regarding these patients' care. The research plan included adult patients with different chronic diseases who were in the chronic or recovery phase

of their diseases and not in the terminal phase, regardless of age, gender, or ethnicity. However, English fluency was required.

Significance of the Study

The present study may be used to fill in the research gap identified in the problem statement by investigating quantitatively and qualitatively individual experiences, perceptions, and needs in health care of adults with chronic diseases. The results of this study provided information, knowledge, and insights which should aid health care providers in better understanding and help patients with chronic diseases in a more supportive, thoughtful, and efficient way.

Positive Social Change Emerging from the Study

CDM requires an ongoing relationship between patients and health care providers over a long-time period. The health team should be able to recognize and comprehend the problems, concerns, and disappointments that patients with chronic diseases have (Heijmans et al., 2001). Patients usually complain that health care providers rarely discuss with them their life styles or ask questions about how the daily management of chronic diseases is performed. When health care providers do not acknowledge patients' experiences and difficulties regarding their chronic disease, treatment, as well as quality of life, of these patients may be affected. Perceived health team behavior and actions can be considered as a force for social change by increasing the quality of patients' lives. Because chronic diseases affects the quality of life of 90 million individuals in the United States (Mathers & Loncar, 2006), the improvement of CDM will ameliorate the life of these patients. By focusing on measurement that refers to the multidimensional nature of

health, the present study will enable health professionals to acquire practical skills in CDM and better promote the quality of patients' lives. The impact of the research findings may be further assessed in daily practice, upon the health team's continuous treatment and management actions.

Summary

There is little known on how patients perceive the changes to service delivery envisaged by chronic care models. Understanding the perceived type of help that these patients get from their health care team is important to promote their adjustment to the illness experience. In this study, I attempted to fill the aforementioned gap in understanding experiences and perceptions of patients with chronic diseases by focusing quantitatively and qualitatively on the patients' views and perceptions of needs and priorities regarding CDM. The PACIC survey was used in order to assess the care of chronic conditions (quantitative component of the study). The dependent variables of the quantitative study were the five subscales of the questionnaire, which are based on the key components of the CCM: patient activation, delivery system design/decision support, goal setting, problem-solving/contextual counseling, and follow-up/coordination. The independent variables were gender, age, education level, race/ethnicity, marital status, insurance status, types and number of chronic conditions, and years lived with these diseases. Additionally, an interview guide with open-ended questions with a wide coverage of interest, including all the aforementioned variables, was used in order to understand perceived CDM (qualitative component of the study).

In Chapter 2, a systematic review of quantitative and qualitative studies of how people live with chronic diseases, focusing on the management of their diseases and the perceived behavior of health care providers will be described.

Chapter 2: The Literature Review

Introduction

Chronic diseases affect the quality of life and well-being of hundreds of millions of individuals globally. Chronic disease will be the leading cause of deaths and disability in the near future (Mathers & Loncar, 2006). Almost every family has at least one family member who suffers from a chronic disease, such as heart disease, stroke, cancer, chronic respiratory disease, diabetes, a mental disorder, or HIV/AIDS. These diseases are described as the most significant among chronic diseases because they may have a major impact on public health as well as economies worldwide (WHO, 2005a). Additionally, chronic diseases' profile is changing at a fast rate, especially in low- and middle-income countries and regions (WHO, 2005a). CDM can be considered a public health matter because chronic disease is a health burden worldwide that unfairly distributed to certain populations (Saaddine et al., 2003; Vinicor, 1994). Therefore, the management of the aforementioned diseases was investigated quantitatively and qualitatively in order to contribute to the development of strategies for possibly improving CDM.

For finding the literature on chronic diseases and their management, the following key words were used separately or in combination: *chronic diseases, heart disease, stroke, cancer, chronic respiratory disease, diabetes, mental disorders, HIV/AIDS, chronic diseases management, acute health care model, chronic care model, mixed methods approach, qualitative study, quantitative study, assessment of chronic diseases management, instruments for chronic diseases management, self-management, and PACIC survey instrument*. Medline (PubMed), Scopus, Cochrane Library, and Google

Scholar were the key electronic databases used for detecting as many possible sources regarding the topic of this dissertation, mostly focusing on the more recent ones (2000 to present). Some textbooks were also reviewed (e.g., Creswell, 2009) in order to better support methodological issues in this study.

Conceptual Framework

Chronic diseases need to be studied from a combination of research approaches, using qualitative as well as quantitative methodologies. The use of different research methods within a single study can provide a richer and deeper understanding of the area under investigation (Corner, 1991). In this study, I extended the understanding of how to best manage chronic diseases by adopting a mixed-methods approach and by assessing patients' experiences, mostly focusing on CDM. The objective ratings by chronic diseases patients regarding the assessment of care for chronic conditions (quantitative section of the study) was the best possible selection of the participants for the qualitative component of the study. Patients' experiences and perceptions regarding CDM were explored with the use of a qualitative case study approach. This approach included the investigation of the phenomenon under study (perceived CDM) with a variety of lenses which allows for multiple facets of the phenomenon to be revealed and understood (Baxter & Jack, 2008).

Description of Chronic Diseases Under Study

Heart Disease

There are many diseases that fall under the general term heart disease. The most common diseases included in heart diseases are chronic heart failure (CHF) and coronary

artery disease (CAD). Heart disease may cause numerous problems regarding the quality of life of the individuals and it is 2 to 5 times more common in males than in females (Rosamond, 2008). CHF occurs when the heart's blood pumping function is compromised, resulting in under-perfusion of tissues (Jeon et al., 2010). It leads to progressive physical and functional deterioration. Patients with CHF often exhibit shortness of breath, tiredness, dizziness, and intermittently unpredictable life-threatening crises, requiring repeated hospitalization (Jeon et al., 2010). There is no cure for CHF.

CAD occurs when a substance builds up in the walls of the arteries (plaque), resulting in more narrow arteries and blocking blood. CAD is the most common cause of death in the United States (McKenzie, 2006) and its prevalence ranges from 7% to 20% in people over 45 years-old (The Centers for Disease Control and Prevention [CDC], 2011). Heart attacks occur when a blood clot cuts off the blood flow completely, resulting in death of the cardiac muscle (CDC, 2011). Over 1.5 million individuals have heart attacks each year in the United States, resulting in 500,000 deaths; each year, approximately 1 million persons in the United States support a person who has suffered a heart attack (National Health and Nutrition Examination Survey [NHANES], 2006).

Prevention is the key to treatment of heart disease. The most common risk factors to heart disease are age, gender, high blood pressure, high serum cholesterol levels, tobacco smoking, excessive alcohol consumption, family history, obesity, a lack of physical activity, and diabetes mellitus (CDC, 2011). Some of these risk indicators such as age, gender, or family history cannot be modified but the rest of the factors may be

eliminated by changing lifestyle, such as adopting a healthier diet and regular physical activity or/with the use of specific drug treatment.

Stroke

A stroke is a sudden interruption in the blood supply of the human brain (The Internet Stroke Center, 2013). After a stroke, some patients are not able to carry out some of the functions of the brain tissues, such as walking, using their hands, or even talking and eating. Strokes may also cause weakness in parts of the human body, such as in the face, arm, leg, and or on one side of the body (The Internet Stroke Center, 2013). Stroke is one of the leading causes of disability in the world, mostly occurring in individuals over the age of 65, and is observed more in males than females (The Internet Stroke Center, 2013).

According to the CDC (2009a), stroke is the third leading cause of death in the United States and it is the leading cause of long-term disability. Approximately 795,000 people in the United States suffer a stroke each year; 600,000 of these are first attacks and 185,000 are recurrent attacks (The Internet Stroke Center, 2013).

The most significant stroke risk factors are similar to heart disease like high blood pressure, obesity, tobacco smoking, and high levels of cholesterol. People with a family history of stroke also have an increased risk of stroke (The Internet Stroke Center, 2013). African Americans have higher rates of stroke than European Americans, even at younger ages (The Internet Stroke Center, 2013). The best way to prevent stroke is by controlling risk factors, including regularly exercise and healthy diet.

Cancer

According to the United States Cancer Statistics (2013) cancer is the second leading cause of death in the United States; more than 565,000 people died of cancer and more than 1.48 million people had a diagnosis of cancer in 2008. Although anyone could suffer from cancer, African Americans are more likely to die from cancer than people of other races United States Cancer Statistics (2013). Cancer survivors usually end up with long-term disabilities; therefore, long term care and support is needed (Philips & Currow, 2010). These complex conditions include permanent disabilities and impaired function and psychological distress and socioeconomic issues, such as difficulties regarding the employment of individuals with cancer (Hewitt et al., 2006).

Cancer prevention could be accomplished by avoiding tobacco, alcohol, exposure to ultraviolet sun rays, eating a diet rich in fruits and vegetables, being physically active, and seeking regular medical care (CDC, 2012). Additionally, periodically screening for breast, cervical, and colorectal cancer could play a preventive role for these diseases by revealing lesions that could be managed before they become cancerous (CDC, 2012).

Chronic Obstructive Pulmonary Disease

Chronic obstructive pulmonary disease (COPD) refers to a group of conditions that cause airflow blockage and breathing-related problems; chronic bronchitis and emphysema are the most frequently occurring COPDs (CDC, 2012). COPD caused an estimated 126,005 U.S. deaths in individuals older than 25 years in 2005 and this was an 8% increase from 116,494 in the year 2000 (CDC, 2008). Further, chronic bronchitis and emphysema prevalence in U.S. adults over the age of 18 years in 2009 (the most current

reporting year) was 44 and 22 cases per 1,000 respectively (U.S. Environmental Protection Agency, 2012). Chronic bronchitis and emphysema prevalence was higher among European American adults than African American adults in a time period of 10 years 1999-2009 (U.S. EPA, 2012)

The long-term management of COPD should involve successfully controlling the following difficult symptoms: shortness of breath (dyspnea), cough, coughing up blood, and chest pain.

COPD prevention could be achieved by controlling risk factors, such as cigarette smoking, exposure to occupational dust and chemicals, exposure to indoor air pollution, and alpha-1 antitrypsin deficiency (University of Maryland. Medical Center [UMM], 2011).

Diabetes

According to Centers of Diseases Control and Prevention (2011), “diabetes is a group of diseases marked by high levels of blood glucose, resulting from defects in insulin production, insulin action, or both”. It is divided into main two types (I and II), but there are also gestational diabetes and other specific types. As far as Type I is concerned, the body's immune system attacks insulin-producing pancreatic cells, therefore patients need insulin injections to survive. It usually occurs in childhood (CDC, 2011a). On the other hand, diabetes Type II is non-insulin-dependent diabetes mellitus (NIDDM) or adult diabetes and it is the most common type, primarily due to lifestyle factors and genetics (CDC, 2011a). Further, gestational diabetes is a type of glucose intolerance diagnosed during pregnancy (CDC, 2011a).

In 2000 the global prevalence of diabetes was 2.8 per 1,000 individuals. In 2010, it is estimated that 285 million people had diabetes with type II, which is 90% of the cases worldwide (Griffin et al, 2000).

Diabetes' incidence has been increased which makes the number of the cases with diabetes almost double by 2030 (Griffin et al, 2000). Diabetes mellitus occurs throughout the world, but is more common in the developed countries (Griffin et al, 2000). The prevalence increases more in Asia and Africa. Approximately 3.8 million people have diabetes mellitus in the United Kingdom (UK). Previous studies report that more than 6.2 million people will have diabetes by 2035 in the UK (Griffin et al, 2000). Diabetes rates have been increasing substantially in North America in the past 20 years (Griffin et al, 2000) and diabetes is also very common among African Americans (CDC, 2011a). Further, it is increasing the potential for the children of diabetic mothers to become diabetic in the future (Griffin et al, 2000).

Untreated diabetes increases the risk of long-term complications, including an increased risk of heart attack, stroke, amputation, and kidney failure (CDC, 2011a). These typically develop after 10 to 20 years. Diabetes is initially managed by medical nutrition therapy (MNT), adoption of healthier daily habits and of course medication to control blood sugar levels.

Mental disorders

Mental illnesses are related to CDM in two ways; first, individuals with mental or substance abuse disorders may also have physical health problems, which sometimes remain undetected or untreated. More specifically, all the types of dementia, such as

Alzheimer's disease, vascular dementia, by changing the structure of the brain and gradually damaging brain cells, result in decline in significant brain abilities, such as memory, thinking speed, mental agility, understanding and several physical functions (NHS, 2012). Dementia has a significant impact on global public health, since it is estimated that globally 24.3 million people currently have dementia, with 4.6 million new cases of dementia every year (Ferri et al., 2005). Also, recent research indicated that the number of people affected with mental illnesses will double to 81.1 million by 2040 (Ferri et al., 2005).

Further, long term substance abuse (e.g. heroin, inhalants, alcohol, steroids) has a significant impact on quality of individual's life. More specifically, substance abuse, as a chronic brain disease, may change specific areas of the brain that are critical to judgment, learning and memory, and behavior control and may also affect significant organs as liver, kidneys, respiratory system and even teeth (National Institute on Drug Abuse, 2011),.

The second way that mental disorders are correlated to CDM is that they may worsen prognosis of other chronic diseases, such as heart disease, stroke, diabetes, HIV/AIDS and cancer; this is mostly attributed to the significant impact that many chronic diseases can have on a person's mental and emotional status. More specifically, depression is one of the most common complications of almost all chronic diseases, resulting in a reduction of the needed energy, which is necessary to manage with changes and treatment schedules, eventually creating a vicious cycle of worsening physical and emotional symptoms.

Acquired Immuno Deficiency Syndrome (AIDS)

Acquired Immuno Deficiency Syndrome (AIDS) is the final phase of the Human Immunodeficiency Virus (HIV) infection, in which a person may have one or more opportunistic infections, certain cancers, or/and a low number of CD4 cells (AIDS.gov, 2012). Nowadays, AIDS is considered as chronic disease mostly attributed to the use of specific medication. Approximately 1.2 million adults and adolescents were living with HIV infection at the end of 2008 in the U.S. (CDC, 2012). By risk group, gay, bisexual, and other men who have sex with men (MSM) of all races remain the population most severely affected by HIV. In 2006, the rates of new HIV infections for black men were shown to be six times higher than the rate for white men (CDC, 2009b). The high rate in African American males is mostly attributed to unprotected sex, IV drug use and risk behaviors associated with incarceration.

U.S. Government has an established AIDS policy and it has successful programs that have worked. These programs focused on providing HIV prevention services through HIV testing, counseling and educational sessions. According to the office of national aids policy (2009), America has made enormous progress in responding to the global HIV/AIDS epidemic. It has helped expand access to treatment, care and prevention for people infected with AIDS. Black women are faced with a number of factors such as at-risk partners or substance abuse that increases their risk for HIV infection. “An effective strategy for reducing the number of new HIV infections among African American women may be to direct prevention efforts to their heterosexual partners” (CDC, 2009b).

Increasing early testing and medical care access may aid in prevention of HIV/AIDS infection among black men and women.

Chronic Diseases Management Models

Traditional and new models

By carefully exploring the literature of chronic diseases, it becomes clear that a variety of aspects and ingredients are needed to be investigated for improving the quality of CDM. Chronic diseases demand complex care models, requiring collaboration between health team and caregivers which traditionally have been disconnected and oriented towards acute care (Kavanagh, 2010). Immediate management of symptoms or complications related to chronic diseases (acute care model) is widely considered as inefficient, since this kind of care is not appropriate to continue for long periods of time and it certainly not address the complex needs of patients with chronic diseases. Consequently, it was necessary to develop new models which are more patient-centered, mostly focusing on the individual needs of each patient with chronic disease(s) as well as on the perceived behavior of health care providers, in order to provide better and constant care to this high risk population group.

Chronic Care Model (CCM)

The CCM (Wagner, 1996) has a broad international acceptance as an approach which focuses on the shift from acute care model to a lifelong model of promotion, prevention and early intervention. The CCM includes both non-communicable chronic diseases (diabetes, heart disease, chronic obstructive pulmonary disease, cancer and mental disorders) and communicable diseases (e.g., HIV/AIDS). Many countries are

engaged in the transition to this model, including US, Ireland, United Kingdom, Canada, Australia, New Zealand, China and India.

The CCM aims at creating empowered and informed chronic disease patients as well as proactive health or/and social care teams (Wilson, 2001). CCM identifies the essential elements such as community, the health system, self-management support, delivery system design, decision support and clinical information systems of a health care system that encourage high-quality chronic disease care. The key in supporting processes is the use of information systems for change. CCM offers a framework that re-orientes healthcare services to effectively deal with the needs and concerns of individuals with chronic disease. Quality improvement teams are working with this model, focusing their efforts and interventions on the four areas contained in the health system such as self-management support, delivery system design, decision support and clinical information systems (Wagner, 2001). CCM was also developed to promote better management of long-term conditions, such as depression, in primary care settings. CCM works directly with primary care physicians in a team approach to identify chronically ill patients to closely monitor, educate and mentor patients about effectively living with their diseases.

The CDM teams support people in the effort to improve the general well-being through the use of the CDM during planned scheduled wellness visits. During these visits patients will have the opportunity to spend time with the primary care physician to discuss the chronic illness, medications and treatment options. The Model can be applied to a variety of chronic diseases, health care settings and target populations. The providers

of the health care can be better supported with evidence-based guidelines and information systems. Also, the health care costs can be lowered through better care delivery.

The use of the CCM appeared to have assisted healthcare teams to provide effective solutions to the growing challenge of CDM. The model has been implemented by a large number of organizations in the United States, the United Kingdom and Sweden. Further, according to studies which evaluated the effect of CCM with the use of meta-analysis, it was observed that there was a 30-60% improvement in the process of care associated with CCM, and a 10-15% improvement in clinical outcomes (Tsai et al., 2005). CCM aims at promoting the fact those patients with chronic diseases make decisions and get more involved with behaviors that affect their health, while diseases' control significantly depend on the effectiveness of self-management. Recently, CCM is becoming a significant strategic framework for innovation throughout the healthcare community. Health care providers, who wish to improve the management of their patients, may consider making the CCM a significant component of their practice.

Quantitative, Qualitative and Mixed Methods Investigation of Chronic Diseases Management

Chronic diseases have already been investigated using both qualitative and quantitative methods in many different studies. Although chronic diseases could be excellent examples of conditions that by their nature need to be studied from a combination of perspectives, using both qualitative and quantitative methods (Casebeer & Verhoef, 1997) to the best of our knowledge, there is lack of studies investigating

experiences and perceptions of patients with chronic diseases regarding CDM using a mixed-methods research approach.

Qualitative approach

Qualitative research can be distinguished from quantitative research in several ways. The quantitative data alone will not be fully addressing the research questions but qualitative approaches can be useful to fully address the research questions (Griffin et al., 2000). Qualitative researches provide detailed perspectives of individuals and descriptions of processes, thereby ensuring a more comprehensive understanding of the phenomenon of interest (Griffin et al., 2000). Many studies attempted to investigate both patients and health care providers' opinions and perceptions regarding CDM. More specifically, Horowitz et al. (2004) illuminated the dynamics of self-regulation processes in patients with congestive heart failure using qualitative methods. The researchers interviewed 19 congestive heart failure patients to characterize these processes and found that patients had limited knowledge of congestive heart failure, failed to recognize and act on symptom exacerbation, and encountered a variety of barriers to care. Findings were used to modify an existing model of self-care to fit the unique experiences of patients with congestive heart failure. The quality incentives included that chronic diseases management (CDM) improves quality of care, motivate professionals and giving the opportunity to exchange experience. The quality incentives could encourage healthcare professionals to participate in particular the conviction that CDM improves quality of care.

Also, Lauvergeon et al. (2012) conducted a qualitative study in order to investigate feasibility of CDM interventions, in terms of barriers, facilitators and incentives to participation in Switzerland. The sample of this study included both chronic patients and health care providers who considered having adequate knowledge and experience of chronic diseases. This study concluded that all stakeholders shared common opinions towards the feasibility of CDM in Switzerland, mostly focusing on barriers linked to the federalist political organization as well as to financing such programs.

Further, Jeon et al. (2010) authored a narrative review of qualitative studies about Chronic Health Failure (CHF), including 65 studies conducted between 1990-2008. According to the results of this review, social isolation, living in fear and losing a sense of control characterized the majority of the patients. Also, access, continuity and quality of care, co-morbid conditions, and personal relationships were identified as significant factors of patients' self-care and self-management.

In another qualitative study by Janse et al. (2005), "differences in perception of health and wellbeing between pediatricians and parents of children with a chronic disease were found, not only at diagnosis but also after a period of follow up".

Regarding the implementation of CCM instead of acute care models, Wilson et al. (2012) performed a qualitative case study, including over ninety patients and family carers ranging in age from children to older people with conditions such as diabetes, respiratory disease, epilepsy, or coronary heart disease. This study mainly concluded that

“patients’ preferences and expectations of chronic disease management were framed by a strongly biomedical discourse alongside the desire for an empathetic approach”.

Quantitative approach

Chronic Diseases Management has been assessed in many quantitative studies, with the use of different surveys and evaluation instruments.

Mackey et al. (2012) conducted a quantitative study investigating the impact of the CCM on medication adherence when patients perceive cost as a barrier. They found that interventions designed to enhance self-care had modest success, suggesting a need to improve modifiable patient-level factors. However, it seemed that CCM improved the self-management of chronic conditions, with the establishment of effective communication between patients and their health care team.

Coleman et al. (2010) conducted a study with 8,005 adults who received primary care in 2006 and 2007 at an urban practice owned. Patients' experience was measured before and after the implementation of the medical home program for a subset of 1,098 patients. This study concluded that “informational and managerial continuity may mitigate deleterious effects of reassignment”, although there is need for further improvement in order to “actively bind reassigned patients to the medical home to improve relational continuity with younger, healthier patients”.

Wallace et al. (2010) investigated the influence of literacy on patient-reported experiences of diabetes self-management support. The purpose of this study was to identify factors associated with experiences of self-management support during primary care encounters. The major findings of this study were that the Patient Assessment of

Chronic Illness Care (PACIC) rating decreased with age and it was higher for women than for men. Also, it was greater for those with more education and greater literacy skills. However, no significant differences were found regarding race, insurance status, duration of disease (diabetes) and the intensity of care management.

Summary

CDM can be considered a public health matter, due to the fact that specific criteria are met, such as high chronic disease burden worldwide and unfair distribution of diseases. The most common chronic diseases are heart disease, stroke, cancer, chronic respiratory disease, diabetes, mental disorder and HIV/AIDS. Chronic diseases demand complex care models, requiring collaboration between the health team and caregivers which traditionally have been disconnected and oriented towards acute care.

CCM identifies the essential elements such as community, the health system, self-management support, delivery system design, decision support and clinical information systems of a health care system that encourage high-quality chronic disease care. CCM offers a framework that re-orientes healthcare services to effectively deal with the needs and concerns of individuals with chronic disease

Chronic diseases have been already investigated using qualitative or quantitative methods in many different studies. Although chronic diseases could be excellent examples of conditions that by their nature need to be studied from a combination of perspectives, using both qualitative and quantitative methods, there is lack of studies investigating experiences and perceptions of patients with chronic diseases regarding

CDM, using a mixed-methods research approach. Such an approach is presented in chapter 3.

Chapter 3: Research Method

Introduction

Researchers have addressed the most significant chronic diseases, focusing on their management and evaluation of this management. There is a detailed body of knowledge regarding CDM and different types of management modeling. However, there is a literature gap in understanding the experiences and perceptions of patients with chronic diseases; therefore, I aimed to fill this gap by focusing quantitatively and qualitatively on the patient views and perceptions of needs of CDM. The use of different research methods within a single study can provide a richer and deeper understanding of the area under investigation (Corner, 1991). Therefore, I aimed to elucidate previous findings and produce new knowledge on CDM in order to enable health professionals to better understand and help patients with chronic diseases in a more supportive and efficient way. In this chapter, I will describe the study design, sample strategy and units, instrumentation and ways to confirm validity, and reliability of research methods and tools.

Setting

In this study, I provided a detailed description of experiences and perceptions of patients with chronic diseases by focusing quantitatively and qualitatively on the patient views and perceptions of needs and priorities regarding CDM. The nature of this study is mixed-method with a quantitative focus. Qualitative research was consistent with understanding how patients perceived CDM; I analyzed patients' own words and perspectives. Objective ratings of care for chronic diseases with the use of an instrument

were used elucidate the emerging themes. The quantitative analysis allowed me to summarize the information obtained during the research process.

Research Design and Rationale

Information obtained with the use of quantitative and qualitative tools was used to answer the following research questions:

1. Based on objective ratings by chronic diseases patients, what is the assessment of care for chronic conditions?
2. For patients with chronic diseases, what themes emerge in their reports regarding perceived CDM and thus their quality of life?

The PACIC survey was used to assess the care of chronic conditions (quantitative component of the study). This survey consisted of five scales and 20 corresponding items. The overall PACIC is scored by averaging scores across all 20 items; the higher the score (maximum 5), the better the care assessment. Subsequently, the patients with the lowest average overall PACIC score were qualitatively interviewed in order to comprehend why they were unsatisfied with CDM (qualitative component of the study). The study started with a quantitative approach and was completed with a qualitative one (quantitative → qualitative). The analysis of the qualitative data contributed to the interpretation of the quantitative assessment of care for chronic conditions.

Role of the Researcher

U.S. health care system face challenges to meet the needs of millions of patients who live with at least one chronic illness (Mathers & Loncar, 2006). Health care workers play a role in managing chronic diseases in general practice and primary health care,

including health assessment, follow-up activities, self-management support, and providing patient education. While this study included a purposeful sampling strategy, my role as researcher included some personal or professional relationships, but there were no supervisory relationships with the subjects of the study. Informed consent was obtained by all of the participants and there were no potential risks because there was no treatment or intervention (see Ethical Concerns section for more details).

Methodology

Sampling Strategy and Participants

Because the nature of this study was a mixed-method approach, the sampling procedure was accomplished in two stages for the quantitative and qualitative parts. The research was based on the principle of purposeful sampling strategy. After obtaining Walden's institutional review board (IRB) approval (check the corresponding section for more details) I obtained the written consent of each potential participant. Participants were individuals aged ≥ 18 years-olds with at least one chronic disease who were also in the chronic or recovery phase of their diseases and not in the terminal phase, regardless of age, gender or ethnicity. The study sample was drawn from one church in Chicago and the surrounding communities with the use of invitation flyers and announcements in social media.

In order to determine the sample size of the quantitative part of the study, statistical power, alpha level, and effect size were considered. Statistical power is the probability that a given statistical test will detect a real treatment effect or real relationship between variables. For the study, a value of 0.80 (80%) for power was

determined, which was an acceptable value. In order to have only a 5% chance that my conclusions will be incorrect, an alpha level was set at 0.05. Effect size was calculated with the use of the following equation: Effect size = Square of the correlation coefficient (r^2); R^2 (from a multiple regression). For determining effect size, data regarding overall PACIC score by gender (correlation coefficient $r=0.23$) from the study of Wallace, Carlson, Malone, Joyner, and Dewalt (2010) was used; thus, 122 participants in each gender group, for a total sample of 244 participants, would be ideal.

Approximately 10 patients with the lowest average overall PACIC score were included in the qualitative part of the study. The principle of saturation was chosen to determine the final sample size, which allows stopping new participant recruitment when the last interviews bring no new insight or information. Furthermore, the follow-up questions were constructed during the interview in response to the answers of the participants by adapting to different response patterns. Each interviewee was asked to complete a confidential questionnaire regarding sociodemographic information. The interviews took place in a private place (e.g., a private office in the church) and lasted for 40 minutes to 1 hour. I audiotaped and transcribed all interviews verbatim.

Instrumentation-Quantitative component

The PACIC survey (validated in 2005, see the corresponding validity section) was tested among a number of patients with chronic diseases and it was useful as a patient-centered measure of the implementation of the CCM (ICIC, 2012). The PACIC has been used worldwide as an instrument to evaluate the delivery of CCM or other chronic diseases management activities for a variety of chronic health conditions including

cancer, diabetes, osteoarthritis, depression, asthma, hypertension, and COPD (ICIC, 2012). No permission was needed for personal or non commercial use of this instrument, with the assumption that the wording or content of the questions cannot be changed or altered. Authorship is attributed to The MacColl Center as follows, and that it will be appeared on each page of the instrument: "Copyright 2004 The MacColl Center for Health Care Innovation, Group Health Cooperative".

The questions focused on perceived management of chronic diseases. The questions were about the care provided by the doctors and nurses, highlighting the elements that encourage high-quality of CDM. PACIC helps the patients to learn about and practice principles of self-management, producing activated and engaged patients. The survey is a combination of patient-related management issues, such as self-management interventions, patient education on lifestyle, regulatory skills, and professionally directed and organizational interventions in order to improve chronic care delivery. The PACIC is an item survey that is divided into five subscales: patient activation (Items 1-3), delivery system design/decision support (Items 4-6), goal setting (Items 7-11), problem-solving/contextual counseling (Items 12-15), and follow-up/coordination (Items 16-20). The dependent variables of the quantitative study were the five subscales of the questionnaire (score), which were based on the key components of the CCM: patient activation, delivery system design/decision support, goal setting, problem-solving/contextual counseling, and follow-up/coordination. The independent variables were gender, age, education level, race/ethnicity, marital status, insurance

status, types and number of chronic conditions, and years lived with these diseases.

PACIC instrument is presented in Appendix A.

Instrumentation-Qualitative Component

The qualitative component of the study, which followed the quantitative section, included an interview guide with open-ended questions with a wide coverage of interest, including all the variables in order to understand perceived CDM. These questions were focused on the patient-health care team interactions and on perceived health care providers' behavior and health care delivery. The questions included an analysis of how the life before chronic diseases was and the description of their current situation with chronic diseases. Some examples of the open-ended questions are the following:

- What is the current situation regarding your chronic disease(s)?
- What your life was before the occurrence of chronic disease? Was it very different than the one you currently live?
- How are you dealing with your chronic disease(s)?
- Does your family adequately support you?
- Do you receive an adequate care for your condition? Which things do you believe are the most important regarding your treatment? Which things do you believe should be changed regarding your treatment and why?
- How your life changed since you knew about your chronic disease for the first time?
- Do you try to think positively about your illness? If so, how has this "positive thinking" been beneficial to you?

- What keeps you happy every day?
- Do you find there are societal pressures on people who are chronically ill?
If so, how do they affect you?
- Are you able to take care of yourself? If not, who is helping you?
- Do you have a good support network?
- Do you talk about your illness with your friends, your family, local support groups or online support groups? If so, which do you find the most helpful?

Improving the quality of care for patients living with a chronic illness is a goal for public health policy makers. Efforts were made to use open-ended questions such as “what” and “how” questions, rather than with potentially constraining “why” types of questions. The interview helped the patients to understand their condition and analyze their disease experiences.

Data analysis plan

Quantitative component: The outcome variables were the scores of the five subscales of the PACIC survey as well as the average overall PACIC score. First, descriptive statistics were calculated in order to estimate the prevalence, mean and median of PACIC scores of the sample. Second, bivariate analysis (parametric or not parametric test according to the distribution of the data) were used to test the strength of associations between independent (gender, age, education level, race/ethnicity, marital status, insurance status, types and number of chronic conditions and years lived with these diseases) and dependent variables (PACIC scores). Finally, the estimates of the

relative risks of overall PACIC score were reported by calculating the odds ratios (ORs) and the corresponding 95% confidence intervals (CIs), using logistic or/and linear regression analyses. The dependent variable was overall PACIC score and independent predictors will be all the aforementioned independent variables. Significant confounders, as well as interactions were retained in the models. Deviance residuals were calculated in order to evaluate the model's goodness-of-fit. All reported probability values (p-values) were compared to a significant level of 5% and the analysis of coded data were carried out using SPSS software version 21.0 (IBM Corp. Released 2012).

Qualitative component: Qualitative data were coded systematically using Microsoft Word software and were analyzed thematically. Microsoft Word can and was used for “coding and retrieving, semi-automated coding and inspection, creating hierarchies of code categories via indexing, global editing of theme codes, coding of ‘face-sheet’ data, exploring relationships between face-sheet codes and conceptual codes, quantifying the frequency of code instances, and annotating text” (LaPelle, 2004). Specific examples and techniques proposed by LaPelle (2004) regarding the management and analysis of key informant interviews, literature reviews and open-ended survey questions were applied in this study. Thematic analysis was selected since it is a widely used approach for detecting, analyzing and reporting themes within qualitative data (Braun & Clark, 2006). The six phases of the used analysis were the following (Braun & Clark, 2006): familiarizing with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and finally producing a scholarly report of the analysis.

Validity and reliability control of the measurements of the study

Quantitative component: PACIC instrument was standardized and validated in 2005; it was concluded that it is a reliable instrument and face, construct, and concurrent validity have been confirmed (Glasgow et al., 2005). Also, several studies have been conducted with the use of this instrument, which has been translated in at least five languages (Danish, Spanish, French, Dutch, and Japanese) (ICIC, 2012). Finally, external validity could be strengthened with the use of multivariate regression analysis, while this analysis is a widely used method to control confounding (Margaritis et al, 2011) and therefore to achieve the maximum validation of the potential risk factors of unsatisfactory PACIC scores.

Qualitative component: In order to achieve the maximum validity and reliability of the analyzed patterns/themes, all coding reports were read independently by me and my dissertation supervisor (V.M.) for discussing similarities and differences in interpretation of the qualitative data.

Ethical concerns

Ethical issues have to do with the risks associated with the nature of both quantitative and qualitative research. Regarding the quantitative component of the study, ethical issues may arise when patients may want to negatively evaluate their health providers as far as CDM is concerned, but they are afraid that this evaluation may impact their treatment or perceived behavior of these providers. Additionally, although this is a non-experimental design, protection of the subjects of the study is still important. The

researcher of this study informed participants about: the purposes of the study, the confidentiality of responses, the voluntary nature of the study, the fact that the obtained results will be used only for research and only the researcher and the dissertation committee will have access to the data and the research would not pose risk to the safety or wellbeing of the participants.

As far as the qualitative section of the study is concerned, invasion of privacy constitutes a significant risk due to the sensitive data often collected and analyzed (Baez, 2002). This situation was addressed with the use of participants P1, P2, P3, etc. coding in order to ensure the anonymity of the participants.

Finally, each participant had the right to withdraw from the study at any point. By adequately addressing all the aforementioned ethical concerns, the researcher obtained Walden University's IRB approval (07-30-13-0113381), prior to the start of the study.

Summary

The present study intended to provide a detailed description of experiences and perceptions of patients with chronic diseases by focusing quantitatively as well as qualitatively on the patient views and perceptions of needs and priorities regarding CDM. The nature of this study is mixed-method with a quantitative focus. First, the Patient Assessment of Chronic Illness care (PACIC) survey was used in order to assess the care of chronic conditions (quantitative component of the study). In brief, this survey consists of five scales and 20 correspondent items. The overall PACIC is scored by averaging scores across all 20 items; the higher the score (maximum 5), the better the care assessment. Subsequently, the patients with the lowest average overall PACIC score were

qualitatively interviewed in order to in depth comprehend why they are unsatisfied with CDM (qualitative component of the study). Thus, the study started with a quantitative approach and was completed with a qualitative one (quantitative → qualitative). The analysis of the qualitative data contributed to the interpretation of the quantitative assessment of care for chronic conditions.

The present research was based on the principle of purposeful sampling strategy. After obtaining Walden's IRB approval and written consent of each potential participant, individuals aged ≥ 18 years-olds with at least one chronic disease were invited to participate in the study. In order to properly determine the sample size of the quantitative part of the study, statistical power, alpha level, and effect size were considered.

Ethical concerns were adequately addressed by specific actions of the researcher in order to obtain Walden's IRB approval.

The outcome variables for the quantitative bivariate and multivariate analyses were the scores of the five subscales of the PACIC survey as well as the average overall PACIC score. On the other hand, qualitative data were coded systematically and were analyzed thematically. The detailed presentation of the analyses of the quantitative and qualitative data/ findings of the study will follow in Chapter 4.

Chapter 4: Results of the Study

Introduction

The purpose of this study was to fill the gap in understanding of the experiences and perceptions of patients with chronic diseases by focusing quantitatively and qualitatively on the patient views and perceptions of needs of CDM. I also aimed to elucidate previous findings and produce new knowledge on CDM in order to enable health professionals to better understand and help patients with chronic diseases in a more supportive and efficient way. In this study, I answered the following research questions:

1. Based on objective ratings by chronic diseases patients, what is the assessment of care for chronic conditions?
2. For patients with chronic diseases, what themes emerge in their reports regarding perceived CDM and thus their quality of life?

This chapter includes the analyses of both quantitative and qualitative data, the main results, and evidence of trustworthiness.

Demographics of the Sample and Data Collection Information

Because the nature of this study was a mixed-method approach (explanatory sequential design, quantitative→qualitative), the purposeful sampling procedure was completed in two stages for the quantitative and qualitative part. After obtaining Walden's IRB approval (07-30-13-0113381), I obtained the written consent of each potential participant. According to statistical power calculations (See Chapter 3 for more details) individuals aged ≥ 18 years-olds with at least one chronic disease, who were also

in the chronic or recovery phase of their diseases and not in the terminal phase, were invited to participate in the study. The study sample was drawn with the use of invitation flyers in public places, invitation announcements posted on Facebook, and from one church in Chicago. Finally, 200 persons participated in the study and completed the PACIC survey to assess the care of chronic conditions (quantitative component of the study). Subsequently, 10 patients with the lowest average overall PACIC score were invited to be included in the qualitative part of the study. Because the principle of saturation was chosen to determine the final sample size, which allows stopping new participant recruitment when the last interviews bring no new insight or information, 11 persons with the lowest average PACIC score were included in the qualitative section. The interviews took place in private places, such as a private office in the church or home of the participant and lasted for 45 minutes to 1 hour. I audiotaped and transcribed all interviews verbatim. Collection of quantitative and qualitative data lasted for approximately 1 1/2 months.

Data Analysis

Quantitative Component

The outcome variables were the scores of the five subscales of the PACIC survey as well as the average overall PACIC score. First, descriptive statistics were calculated in order to estimate the prevalence, mean, and median of PACIC scores of the sample. Second, bivariate analysis (nonparametric tests while the data were not normally distributed) were used to test the strength of associations between independent (gender, age, education level, race/ethnicity, marital status, insurance status, types and number of

chronic conditions, and years lived with these diseases) and dependent variables (PACIC scores). Finally, the estimates of the relative risks of overall PACIC score were reported by calculating the odds ratios (ORs) and the corresponding 95% confidence intervals (CIs), using binary logistic regression analysis. The dependent variable was overall PACIC score transformed into categorical variable (high and low PACIC score) using the mean value of the overall PACIC score of the sample as the cut-off point. The independent predictors were all the aforementioned independent variables. Significant confounders, as well as interactions, were retained in the models. Deviance residuals were calculated in order to evaluate the model's goodness-of-fit. All reported probability values (p -values) were compared to a significant level of 5% and the analysis of coded data was carried out using SPSS software version 21.0 (IBM Corp. Released 2012).

Qualitative Component

Qualitative data were coded systematically using Microsoft Word software and were analyzed thematically, as described in Chapter 3. Thematic analysis was selected because it is a widely used approach for detecting, analyzing, and reporting themes within qualitative data (Braun & Clark, 2006). The six phases of the used analysis were the following (Braun & Clark, 2006): familiarizing with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing a scholarly report of the analysis. According to participants' answers, several codes were generated such as medications, support, control of life, changes due to the disease, family, doctor, support group, treatment, and religious beliefs. The major themes emerged were importance of medication, importance of family, importance of religious

beliefs, and a lack of support groups, which will be more analyzed in the Results section- Qualitative component (Table 10).

Results-Quantitative Component (Research Question 1)

The results of the quantitative section of this study are summarized in Tables 1-9. In general, the overall PACIC score was found relatively high (3.47 ± 1.08), and the lower score was detected in follow-up subscale score (3.27 ± 1.23). More specifically: Table 1 is presented by gender; The Mann-Whitney U test was used to compare differences between two independent groups: male and female. Ninety two males and 108 females were included in my study. Because the p value was greater than 0.05 in all cases, no significant differences were detected.

In Table 2, the overall PACIC score and its subscales are presented by age group. Kruskal-Wallis was used to detect potential statistical differences. According to the results, participants aged 71 through 80-years-old had the highest overall PACIC score, but also these differences were not statistical significant.

In Table 3, the overall PACIC score and its subscales are presented by educational level. Kruskal-Wallis was used to detect potential statistical differences. According to the analysis, overall PACIC score ($p < 0.018$) as well as goal setting ($p < 0.019$), problem-solving ($p < 0.021$), and follow up ($p < 0.008$) scores were found to be significantly affected by the educational level of the participants. In order to detect the exact differences among educational level groups, post hoc analyses/multiple comparisons (Mann-Whitney U test) were performed. Thus, regarding overall PACIC, goal setting, problem-solving, and follow-up scores, those who hold a doctoral degree had significantly higher mean scores

(3.97, 3.88, 4.08, 4.10 respectively) compared to all the rest of the participants (p value ranged between 0.007-0.05), besides the ones who obtained no education, where no statistical differences were detected.

In Table 4, the overall PACIC score and its subscales are presented by race. Kruskal-Wallis was used to detect potential statistical differences. According to the analysis, overall PACIC score, as well as all subscales scores, were found to be significantly affected by race ($0.003 < p < 0.032$). In order to detect the exact differences among race groups, posthoc analyses/multiple comparisons (Mann-Whitney U test) were performed. Thus, European American participants had significantly lower PACIC scores (overall and subscales scores) compared to their African American counterparts.

In Table 5, the overall PACIC score and its subscales are presented by marital status group. Kruskal-Wallis was used to detect potential statistical differences. According to the results, divorced participants had the lower overall PACIC score, but these differences were not statistically significant.

In Table 6, the overall PACIC score and its subscales are presented by insurance status group. The Mann-Whitney U test was used to detect potential statistical differences. According to the results, uninsured participants had the lower overall PACIC score, but these differences were not statistically significant.

In Table 7, the overall PACIC score and its subscales are presented by number of chronic diseases group. The Kruskal-Wallis U test was used to detect potential statistical differences. According to study results, patients having at least four chronic diseases

seemed to have the highest overall PACIC score, but these differences were not statistically significant.

In Table 8, mean, standard deviations, maximum, and minimum of years of having one, two, three, or four chronic diseases are presented. According to Spearman's rho correlation test, the overall PACIC score appeared not to significantly affect any of the categories above.

In Table 9, the estimates of the relative risks of overall PACIC score are reported by calculating the ORs and the corresponding 95% CIs using binary logistic regression analysis. The dependent variable was PACIC scores, transformed to a binary variable using mean value as cut off point. Independent predictors were gender, age, education level, race/ethnicity, marital status, insurance status, and types and number of chronic conditions and years lived with these diseases. The Hosmer and Lemeshow test supported the model ($p>0.05$). Those who hold a doctoral degree were over eight times more likely to have higher mean score ($OR: 1/0.123=8.13, p<0.027$) compared to all the rest of the participants.

Table 1

Overall PACIC Score and its Subscales by Gender

		Overall PACIC score	Patient activation	Delivery system design	Goal setting	Problem solving	Follow up
Male	Mean	3.5277	3.7355	3.6630	3.4674	3.5897	3.3326
	N	92	92	92	92	92	92
	SD	1.06772	1.51552	1.15099	1.20230	1.12513	1.24186
Female	Mean	3.4324	3.4877	3.6358	3.4370	3.4931	3.2241
	N	108	108	108	108	108	108
	SD	1.03204	1.24424	1.20015	1.26288	1.17830	1.21015
Total	Mean	3.4763	3.6017	3.6483	3.4510	3.5375	3.2740
	N	200	200	200	200	200	200
	SD	1.04703	1.37769	1.17493	1.23239	1.15227	1.22295
<i>p value, Mann-Whitney U test</i>		0.351	0.345	0.936	0.682	0.619	0.478

Table 2

Overall PACIC Score and its Subscales by Age

Age		Overall PACIC score	Patient activation	Delivery system design	Goal setting	Problem solving	Follow up
18-30	Mean	3.2500	3.4063	3.3958	3.1750	3.3281	3.0813
	N	32	32	32	32	32	32
	Std. Deviation	0.90134	1.14138	1.14984	1.00931	1.03845	0.96501
31-40	Mean	3.4140	3.6667	3.3876	3.4605	3.3837	3.2558
	N	43	43	43	43	43	43
	Std. Deviation	1.15534	1.19965	1.37231	1.26607	1.35659	1.24925
41-50	Mean	3.5674	4.2319	3.7391	3.3130	3.5652	3.3217
	N	23	23	23	23	23	23
	Std. Deviation	0.88928	2.10443	0.96377	1.01592	1.04506	1.16578
51-60	Mean	3.5781	3.4306	3.9236	3.6875	3.7813	3.1875
	N	48	48	48	48	48	48
	Std. Deviation	0.95850	1.33326	0.98988	1.33809	0.96291	1.29969
61-70	Mean	3.3467	3.4111	3.5778	3.2267	3.3667	3.2733
	N	30	30	30	30	30	30
	Std. Deviation	1.23113	1.29450	1.31578	1.38039	1.33703	1.34982
71-80	Mean	3.5031	3.4375	3.6875	3.5000	3.5156	3.4250
	N	16	16	16	16	16	16
	Std. Deviation	1.21332	1.38628	1.25000	1.26491	1.18134	1.34437
81 and above	Mean	4.2750	4.2917	4.3333	4.2250	4.3438	4.2250
	N	8	8	8	8	8	8
	Std. Deviation	0.55870	0.41547	0.50395	0.87137	0.49888	0.82419
Total	Mean	3.4763	3.6017	3.6483	3.4510	3.5375	3.2740
	N	200	200	200	200	200	200
	Std. Deviation	1.04703	1.37769	1.17493	1.23239	1.15227	1.22295
<i>p value, Kruskal Wallis test</i>		0.157	0.402	0.261	0.194	0.214	0.264

Table 3

Overall PACIC Score and its Subscales by Education level

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		Overall PACIC Score	Patient activation	Delivery system design	Goal setting	Problem solving	Follow up
No education	Mean	3.1500	3.3333	3.4583	3.1750	3.4688	2.5750
	N	8	8	8	8	8	8
	Std.	1.44469	1.27242	1.57296	1.52480	1.51444	1.72523
	Deviation						
Up to High school	Mean	3.5893	3.6067	3.7453	3.6764	3.6348	3.3618
	N	89	89	89	89	89	89
	Std.	1.03459	1.25384	1.16235	1.28753	1.17082	1.18009
	Deviation						
Associate degree	Mean	3.6625	3.9773	3.7121	3.4864	3.7159	3.5773
	N	44	44	44	44	44	44
	Std.	0.94550	1.76149	1.11274	1.12013	1.10178	1.03089
	Deviation						
BS degree	Mean	3.1134	3.3252	3.4553	3.0537	3.1768	2.7902
	N	41	41	41	41	41	41
	Std.		1.18904	1.18499	1.03153	1.05215	1.22062
	Deviation	0.96054					
Master degree	Mean	2.7688	2.8750	3.1250	2.5250	2.7188	2.7750
	N	8	8	8	8	8	8
	Std.	1.39718	1.40224	1.50066	1.41800	1.30547	1.61930
	Deviation						
Doctoral degree	Mean	3.9650	3.8333	3.8667	3.8800	4.0750	4.1000
	N	10	10	10	10	10	10
	Std.	0.74835	1.03339	0.93227	1.00753	0.60150	0.62716
	Deviation						
Total	Mean	3.4763	3.6017	3.6483	3.4510	3.5375	3.2740
	N	200	200	200	200	200	200
	Std.	1.04703	1.37769	1.17493	1.23239	1.15227	1.22295
	Deviation						
<i>p value, Kruskal Wallis test</i>		0.018	0.218	0.637	0.019	0.21	0.008

Table 4

Overall PACIC Score and its Subscales by Race

Race		Overall PACIC score	Patient activation	Delivery system design	Goal setting	Problem solving	Follow up
White	Mean	3.1929	3.3673	3.4354	3.1143	3.2500	2.9755
	N	98	98	98	98	98	98
	Std.	1.14954	1.28654	1.23189	1.24288	1.23835	1.30258
	Deviation						
Black or African American.	Mean	3.8247	3.9644	3.9244	3.8587	3.8433	3.6320
	N	75	75	75	75	75	75
	Std.	0.86733	1.46897	1.10632	1.19357	0.99981	1.03560
	Deviation						
Asian	Mean	3.4250	2.1667	3.8333	3.5000	3.8750	3.5000
	N	2	2	2	2	2	2
	Std.	1.23744	1.64992	1.17851	0.98995	0.88388	1.55563
	Deviation						
Other	Mean	3.5460	3.5467	3.6400	3,5440	3.7200	3.3520
	N	25	25	25	25	25	25
	Std.	0.80828	1.21289	1.02704	,96180	1.01119	1.16659
	Deviation						
Total	Mean	3.4763	3.6017	3.6483	3.4510	3.5375	3.2740
	N	200	200	200	200	200	200
	Std.	1.04703	1.37769	1.17493	1.23239	1.15227	1.22295
	Deviation						
<i>p value, Kruskal Wallis test</i>		0.004	0.032	0.031	0.003	0.009	0.014

Table 5

Overall PACIC Score and its Subscales by Marital Status

Marital Status		Overall PACIC score	Patient activation	Delivery system design	Goal setting	Problem solving	Follow up
Single	Mean	3.5774	3.7439	3.7561	3.5146	3.6646	3.3634
	N	82	82	82	82	82	82
	Std.	0.98533	1.54343	1.11117	1.13138	1.08313	1.11383
	Deviation						
Married	Mean	3.3747	3.4561	3.5333	3.3600	3.4211	3.2084
	N	95	95	95	95	95	95
	Std.	1.10162	1.26234	1.22946	1.33101	1.20574	1.31146
	Deviation						
Separate	Mean	3.7583	3.6667	3.8333	3.8333	3.7500	3.7000
	N	6	6	6	6	6	6
	Std.	1.00221	1.39841	1.32916	1.09848	1.07238	1.08628
	Deviation						
Widow	Mean	3.4821	3.6667	3.8333	3.6000	3.5357	3.0000
	N	14	14	14	14	14	14
	Std.	1.12705	1.21247	1.19650	1.24283	1.21234	1.42289
	Deviation						
Divorced	Mean	3.3333	3.8889	3.1111	3.1333	3.3333	3.3333
	N	3	3	3	3	3	3
	Std.	0.88081	1.01835	0.83887	1.28582	1.52753	0.11547
	Deviation						
Total	Mean	3.4763	3.6017	3.6483	3.4510	3.5375	3.2740
	N	200	200	200	200	200	200
	Std.	1.04703	1.37769	1.17493	1.23239	1.15227	1.22295
	Deviation						
<i>p value, Kruskal Wallis test</i>		0.750	0.830	0.502	0.634	0.784	0.858

Table 6

Overall PACIC Score and its Subscales by Insurance Status

Insurance Status		Overall PACIC score	Patient activation	Delivery system design	Goal setting	Problem solving	Follow up
Insured	Mean	3.5065	3.6078	3.6972	3.4353	3.5882	3.3373
	N	153	153	153	153	153	153
	Std.	1.06713	1.22899	1.17376	1.17879	1.14330	1.24720
	Deviation						
Not Insured	Mean	3.3777	3.5816	3.4894	3.5021	3.3723	3.0681
	N	47	47	47	47	47	47
	Std.	0.98322	1.79434	1.17718	1.40550	1.17824	1.12851
	Deviation						
Total	Mean	3.4763	3.6017	3.6483	3.4510	3.5375	3.2740
	N	200	200	200	200	200	200
	Std.	1.04703	1.37769	1.17493	1.23239	1.15227	1.22295
	Deviation						
<i>p value, Mann Whitney</i>		0.299	0.284	0.213	0.899	0.241	0.098
<i>U test</i>							

Table 7

Overall PACIC Score and its Subscales by Number of Chronic Conditions

Number of Chronic Conditions		Overall PACIC score	Patient activation	Delivery system design	Goal setting	Problem solving	Follow up
1	Mean	3.5004	3.6268	3.5470	3.5009	3.5449	3.3607
	N	117	117	117	117	117	117
	Std. Deviation	0.96632	1.40071	1.14676	1.18077	1.06046	1.11270
2	Mean	3.3475	3.5028	3.7797	3.2712	3.3983	3.0305
	N	59	59	59	59	59	59
	Std. Deviation	1.19321	1.38737	1.29486	1.32288	1.31726	1.40139
3	Mean	3.5588	3.5490	3.7255	3.4941	3.6471	3.4588
	N	17	17	17	17	17	17
	Std. Deviation	1.15153	1.39414	1.07520	1.36769	1.20888	1.29762
4	Mean	3.9571	4.1429	4.0476	4.0286	4.3214	3.4286
	N	7	7	7	7	7	7
	Std. Deviation	0.73792	0.87891	0.70523	0.86740	0.82556	1.15717
Total	Mean	3.4763	3.6017	3.6483	3.4510	3.5375	3.2740
	N	200	200	200	200	200	200
	Std. Deviation	1.04703	1.37769	1.17493	1.23239	1.15227	1.22295
<i>p value, Kruskal Wallis test</i>		0.611	0.596	0.284	0.464	0.217	0.544

Table 8

Descriptive Statistics for Years of having One/Two/Three/Four Chronic Diseases

	N	Minimum	Maximum	Mean	Std. Deviation
Years Lived With One Disease	200	1.00	48.00	9.5450	9.20225
Years Lived With Two Diseases	83	1.00	35.00	8.6747	8.37841
Years Lived With Three Disease	26	.00	58.00	12.6154	14.05440
Years Lived With Four Diseases	7	1.00	15.00	8.0000	5.65685

Table 9

Binary logistic regression having as dependent variable overall PACIC score and as predictors gender, age, race, marital status, educational level, insurance status, number of chronic conditions and years with at least one chronic condition.

	B	S.E.	Wald	df	p value	Odds Ratio	95% CI for Odds Ratio	
							Lower	Upper
Gender(1)	.174	.362	.231	1	.631	1.190	.585	2.419
Age			5.191	6	.520			
Age(1)	-1.833	1.067	2.950	1	.086	.160	.020	1.295
Age(2)	-1.539	1.030	2.233	1	.135	.215	.029	1.615
Age(3)	-.786	1.081	.529	1	.467	.456	.055	3.789
Age(4)	-1.254	1.010	1.540	1	.215	.285	.039	2.067
Age(5)	-1.459	1.024	2.030	1	.154	.232	.031	1.730
Age(6)	-.880	1.078	.667	1	.414	.415	.050	3.427
Education level			10.049	5	.074			
Education level(1)	-2.572	1.343	3.671	1	.055	.076	.005	1.061
Education level(2)	-1.117	.949	1.386	1	.239	.327	.051	2.101
Education level(3)	-1.188	.985	1.455	1	.228	.305	.044	2.101
Education level(4)	-2.094	.947	4.889	1	.055	.102	.011	1.053
Education level(5)	-2.246	1.172	3.669	1	.027	.123	.019	0.788

Race			13.297	3	.004			
Race(1)	-.865	.592	2.138	1	.144	.421	.132	1.342
Race(2)	.832	.546	2.326	1	.127	2.298	.789	6.698
Race(3)	-.024	1.694	.000	1	.988	.976	.035	27.017
Marital Status			3.764	4	.439			
Marital Status(1)	1.112	1.416	.617	1	.432	3.041	.189	48.818
Marital Status(2)	1.605	1.425	1.268	1	.260	4.975	.305	81.234
Marital Status(3)	.258	1.642	.025	1	.875	1.294	.052	32.310
Marital Status(4)	1.868	1.579	1.399	1	.237	6.476	.293	143.097
Insurance Status(1)	.778	.423	3.378	1	.066	2.178	.950	4.995
Number of Chronic Conditions			4.890	3	.180			
Number of Chronic Conditions(1)	-1.339	1.019	1.727	1	.189	.262	.036	1.931
Number of Chronic Conditions(2)	-1.658	1.027	2.603	1	.107	.191	.025	1.428
Number of Chronic Conditions(3)	-2.318	1.145	4.097	1	.051	.098	.010	.929
Number of Chronic Conditions			1.820	2	.402			
Number of Chronic Conditions(1)	.341	.418	.665	1	.415	1.406	.620	3.189
Number of Chronic Conditions(2)	.703	.524	1.803	1	.179	2.020	.724	5.639
Constant	2.172	2.169	1.003	1	.317	8.779		

Results-Qualitative component (Research Question 2)

Demographics of interviewees: they were 5 men and 6 women, and most of the participants (7) aged above 60 years-old. Their overall PACIC score ranged between 1.00 to 1.25. Also, all 11 participants were white and the great majority (9) was insured. Finally, 8 out of the 11 participants had at least 2 chronic diseases.

In the analysis the four main themes manifested and were labeled as following (Table 10): importance of medication, importance of family, importance of religion beliefs and lack of support groups.

Importance of medication: seven of the interviewees described that medication is the most important thing regarding the treatment of their disease. Also, all of them stated that taking their medication in regular basis is significant to keep their disease under control. However, two of the participants stated that medication may result in some weariness and thus they need to keep up their efforts up to tolerate the treatment.

Importance of family: nine participants stated that their family significantly helps them to deal with diseases' consequences as well as to the receipt of treatment. Also, two interviewees mentioned that some family members help them better understand doctor's instructions and guidance regarding the treatment of their diseases.

Importance of religion beliefs: religion and faith and God seem to be significant factors as far as the management of diseases is concerned. More specifically, "faith", "Lord" and religious beliefs appeared to help patients to tolerate the consequences of the diseases and of the treatment. Also, six participants said that God and family are the most helpful factors to manage their disease. Finally, one interviewee mentioned he does not believe in "positive thinking" and that "the Lord gives him positive thoughts".

Lack of support groups: all 11 of the interviewed participants stated that they did not participate in any well organized support groups/networks regarding the management of their diseases and that family and religious groups play that role. However, according to

their responses, it is not clear if there is lack of these groups or the participants were not adequately approached to participate in these groups.

Table 10

Main categories / subcategories of thematic analysis and selected coded extracts on management of chronic diseases according to 11 adults

Theme/category	Subcategory	Selected extract
<i>Importance of medication</i>	<i>Control of disease</i>	<p>“ I think taking the medicine is the most important thing ” P1</p> <p>“ It is controlled when I am taking the medication ” P3</p> <p>“I eat all my medicine and I don't need to ‘deal’ with my disease at all. I don't feel sick” P10</p> <p>“Take my medicine on time is one of the most significant things regarding my treatment” P6</p> <p>“I just trusted the medicine will help me” P7</p>
	<i>Fatigue</i>	<p>“It is okay now but so tired on Monday because I take strong medicine on Saturday and Sunday” P4</p> <p>“ I think I have too much medication ” P10</p> <p>“I think I have too much medication!” P11</p>
<i>Importance of family</i>	<i>Support</i>	<p>“Yes my family does support me.” P2</p> <p>“My family is most helpful regarding my disease” P4</p> <p>“ Seeing my kids happy, keep me happy every day” P2</p>
	<i>Help in understanding disease management</i>	<p>“ ...just with my daughter because she helps me understand doctor orders and health issues.” P1</p>
<i>Importance of religion Beliefs</i>		<p>“My relationship with God and my family keeps me happy every day” P8</p> <p>“ Faith and take my medicine on time are most important things regarding my treatment” P6</p> <p>“ My relationship with the Lord...keeps me happy every day” P5</p> <p>“ My Christian faith” P7</p>
<i>Lack of support groups</i>		<p>“Friends and family are my support network” P1</p> <p>“Sometimes I talk about it with friends and family. I am not involved with any local support groups or online support groups ” P10</p> <p>“A good support network is my family” P3</p>

Evidence of Trustworthiness

As far as the quantitative component of this study is concerned, PACIC instrument is a reliable and standardized survey and construct as well as content validity

have been already confirmed (Glasgow et al., 2005). Also, with the use appropriate bivariate tests and multivariate regression analysis to control confounding, the external validity have been established as much as possible. Regarding qualitative component, my dissertation supervisor (V.M) and I reported all the codes independently to achieve the maximum validity and reliability of the analyzed patterns/themes. Also, the similarities and differences in interpretation of the qualitative data were discussed prior to the presentation of the qualitative data.

Summary

Since the nature of this study was mixed-method approach, purposeful sampling procedure was completed in two stages: first, for the quantitative part and second, for the qualitative part. The study sample was drawn with the use of invitation flyers in public places, invitation announcements posted on Facebook and from one church in Chicago. Finally, 200 persons participated in the study and completed the PACIC survey to assess the care of chronic conditions. Subsequently, 10 patients with the lowest average overall PACIC score were invited to be included in the qualitative part of the study. Since the principle of saturation was chosen to determine the final sample size, 11 persons were finally included in the qualitative section. Research Question 1 (quantitative component of the study): the overall PACIC score was found relatively high (3.47 ± 1.08), while the lower score was detected in Follow up subscale score (3.27 ± 1.23). Regarding overall PACIC, goal setting, problem solving and follow up scores, those who hold a doctoral degree seemed to have significantly higher mean score (3.97, 3.88, 4.08, 4.10 respectively) compared to all the rest of the participants (p value ranged between 0.007-

0.05), besides the ones who obtained no education, where no statistical differences were detected. Also, white participants had significantly lower PACIC scores (overall and subscales scores) compared to Black-African American counterparts. Research Question 2 (qualitative component of the study): in the analysis the main themes emerged and were labeled as following; importance of medication, importance of family, importance of religion beliefs and lack of support groups. Importance of medication and religion beliefs found to be reported by almost all of the participants. In conclusion, educational level, race, medication and religion beliefs appeared to be the most significant factors affecting the perception of CDM. In Chapter 5, interpretation of the findings, limitations of the study and social change implications will be provided.

Chapter 5: Discussions, Conclusions, and Recommendations

Introduction

A more patient-centered health care system, mostly focusing on the individual needs of each patient with chronic disease(s) as well as on the perceived behavior of health care providers, would be beneficial for both patients and families. For this purpose, an in-depth comprehension of patients' perceptions about CDM is essential. Therefore, the main aim of this study was to investigate and comprehend quantitatively and qualitatively perceived CDM of patients with various chronic diseases.

According to the main results of the study, the overall PACIC score was found to be relatively high (3.47 ± 1.08), probably due to the relatively satisfactory level of provided health care in United States, while the lower score was detected in the follow-up subscale score (3.27 ± 1.23). Regarding overall PACIC, goal setting, problem-solving, and follow-up scores, those who held a doctoral degree had significantly higher mean score (3.97, 3.88, 4.08, 4.10 respectively) compared to all the rest of the participants (p value ranged between 0.007-0.05), besides the ones who obtained no education, where no statistical differences were detected. Also, those who held a doctoral degree were over eight times more likely to have higher mean overall PACIC score ($OR: 1/0.123=8.13$, $p<0.027$) compared to all the rest of the participants.

Further, European American participants had significantly lower PACIC scores (overall and subscales scores) compared to their African American counterparts. On the other hand, in the qualitative component of the study, I found that four main themes manifested as the following: importance of medication, importance of family, importance

of religious beliefs, and a lack of support groups. Importance of medication and religious beliefs was by almost all of the participants. Educational level and race and hand medication and religion beliefs appeared to be the most significant factors affecting the perception of CDM, according to quantitative and qualitative results.

Interpretation of the Findings

New Insights and Recommendations for Further Research and For Practice

According to the quantitative analysis of the data, European American participants had significantly lower PACIC scores (overall and subscales scores) compared to their African American counterparts. This may partly be attributed because European American persons of this study were of higher educational and socioeconomical background and they may had higher expectations and requirements from health system compared to African American individuals. These expectations can be the subject of future studies with a qualitative focus.

Many of the interviewees considered religion and spirituality as an important factor of CDM and individuals with chronic conditions who appeared to find comfort from their religious and spiritual beliefs were more satisfied with their lives and they managed possible pain more successfully. The more the patients were religiously involved (e.g., practices, support from religious community), the more adherent they were and more willing to take care of themselves and taking the medication. Many participants were recruited from a church in Chicago; therefore, their religious beliefs may play a role in their lives. This result may extend knowledge on CDM perceptions of

patients because there is a lack of studies on the role of religion and spirituality and the management of chronic diseases.

Medication also appeared to be a factor in CDM. Almost all of the participants of the qualitative component reported that the chronic diseases can be adequately controlled with the use of the appropriate medicines. One plausible explanation for this was that some participants who have previously lived in Egypt or other countries with relatively inferior medical health care compared to the care in the United States or other developed countries reported that they felt that medication is a “gift” that should be received. This finding can be further explored in future research in order to provide patients the best possible medication with the less possible side effects. However, medication is not the only solution in every health problem and there are other more natural ways to prevent/manage diseases, such as physical activity, healthy diet, and lifestyle, as some of the interviewees mentioned.

Although there are a lot of support groups that can assist persons with chronic diseases, many interviewees indicated that they have not received any help from such groups, probably due to a lack of knowledge regarding the existence of the groups or because they did not seek for any assistance from these groups. This result emphasizes the need of the better promotion and communication of these groups by public health leaders or policy-makers in order for the patients to be involved with these groups as much as possible.

A recommendation for practice could be that health teams can include the PACIC survey in their daily practice because this instrument is very useful to assess perceived

CDM and satisfaction of patients, according to the results of this study. Also, another practical recommendation may be the inclusion of social workers or similar professionals in the health teams, in order to assess and ensure the best possible perceived CDM.

Confirmation of Results of Previous Studies

In the quantitative component of this study, I found that those who held a higher degree (doctoral degree) had significantly higher PACIC scores and this is in accordance to previous research (Wallace et al., 2010). People with higher degrees usually have higher incomes and better opportunities for health insurance; thus, they may receive a high level of medical treatment (Cutler & Lleras-Muney, 2010).

According to the almost all the qualitative interviews, family appeared to help participants to deal with diseases' consequences as well as to the receipt of treatment, regardless of the perceived behavior of health team. The importance of personal relationships has been documented in CDM (Jeon et al., 2010) and aligns with this study's results.

Limitations of the Study

In this study, I examined the perceived CDM within the United States only, using a convenience study sample recruited from a church in Chicago and surrounding communities. Therefore, generalization to populations with chronic diseases outside of the United States, where health system and socioeconomic factors may differ, should be made with caution. Also, since there are different populations within United States and this study was conducted in specific communities of Chicago, generalization to other American communities should be made very carefully. Additionally, certain information

was retrieved from patients' questionnaires and narratives and is, therefore, subject to recall bias. Finally, some researchers, especially with a positivist background, have raised concerns about what kind of research questions are addressed using qualitative analysis; there is a controversy about whether there are adequate methodological standards in order to achieve the best possible validity and reliability of qualitative data (Poses & Isen, 1998).

Positive Social Change Implications

Perceived type of help that persons with chronic diseases receive may be considered as a force for social change by increasing the quality of patients' lives. Understanding patients' experiences regarding the management of their diseases is important to promote their adjustment to the illness experience. I attempted to provide an assessment of care of chronic conditions with the use of the PACIC survey of participants to explore the experiences and feelings of those who had the lowest PACIC scores. According to the results of the study, with the empowerment of the role of families, support groups, and effective medications in CDM, the quality of life of patients may be improved. Also, religion and spirituality should be further investigated, while they appeared to also play a role in CDM. Practical recommendations may focus both on patients and health care providers. Patients should be better informed about the use of organized support groups in their communities and should be also encouraged to seek assistance from their families, adopting healthier lifestyle at the same time. Health care providers may be better informed on the individual characteristics (e.g., religious beliefs) and may also further develop an empathetic personal relationship with their patients.

Conclusions

Investigating and comprehending quantitatively and qualitatively perceived CDM of patients with various chronic diseases may enable health professionals to better understand and help patients with chronic diseases in a more supportive and efficient way. In this study, I revealed that, according to overall PACIC score, the level of perceived care of chronic conditions in an adult population in the United States is relatively high. Also, educational level, race, medication, and religion beliefs appeared to be the most significant factors affecting the perception of CDM. Empowerment of the role of families, support groups, and effective medications in CDM may improve the quality of life of this population group.

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Appendix A. Patient Assessment of Chronic Illness Care.

Patient Assessment of Chronic Illness Care Survey

Staying healthy can be difficult when you have a chronic condition. We would like to learn about the type of help with your condition you get from your health care team. This might include your regular doctor, his or her nurse, or physician's assistant who treats your illness. Your answers will be kept confidential and will not be shared with your physician or clinic.

Over the past 6 months, when I received care for my chronic conditions, I was:

	None of the time	<u>A Little of the Time</u>	Some of the Time	Most of the Time	Alw ays
B1. Asked for my ideas when we made a treatment plan.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B2. Given choices about treatment to think about.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B3. Asked to talk about any problems with my medicines or their effects.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B4. Given a written list of things I should do to improve my health.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B5. Satisfied that my care was well organized.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B6. Shown how what I did to take care of myself influenced my condition.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B7. Asked to talk about my goals in caring for my condition.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B8. Helped to set specific goals to improve my eating or exercise.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

B9. Given a copy of my treatment plan.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B10. Encouraged to go to a specific group or class to help me cope with my chronic condition.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B11. Asked questions, either directly or on a survey, about my health habits.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

Over the past 6 months, when I received care for my chronic conditions, I was:

	None of the time	<u>A Little of the Time</u>	Some of the Time	Most of <u>the Time</u>	Alw ays
B12. Sure that my doctor or nurse thought about my values, beliefs, and traditions when they recommended treatments to me.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B13. Helped to make a treatment plan that I could carry out in my daily life.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B14. Helped to plan ahead so I could take care of my condition even in hard times.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B15. Asked how my chronic condition affects my life.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B16. Contacted after a visit to see how things were going.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B17. Encouraged to attend programs in the community that could help me.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

B18. Referred to a dietitian, health educator, or counselor.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B19. Told how my visits with other types of doctors, like an eye doctor or other specialist, helped my treatment.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B20. Asked how my visits with other doctors were going.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

Appendix B. Research Documents

Flyers Invitation

Invitation to participate in a research regarding the management of chronic diseases.

Dear all,

My name is Suzan Awad and I am a doctoral student at Walden University and also a medical student. Therefore, I would like to kindly invite you to take part in my research study of understanding experiences and perceptions of patients with chronic diseases by investigating patients' views and perceptions of needs and priorities regarding Chronic Disease Management. The study will include a completion of a brief questionnaire of 20 simple questions regarding the management of your disease and a potential 30 to 40 minutes interview also regarding the management of your disease. Although all the participants of the study will complete the questionnaire, only few will be invited to participate to the interview and they will be notified in a timely manner.

I am inviting adults, aged at least 18 years old, with at least one chronic disease, who are also in the chronic or recovery phase of their diseases, regardless of age, gender or ethnicity. Example: a diabetic patient who has his/her disease under control and receives regularly insulin. The purpose of this study is to understand experiences and perceptions of patients with chronic diseases by investigating patients' views and perceptions of needs and priorities regarding Chronic Disease Management. Some more details and contact information: You may take as much time as you need to decide to participate in the study and to ask any questions now or afterwards via phone or email

[REDACTED] and suzan.awad@waldenu.edu). If you agree to participate, you will sign an informed consent form, which includes all the needed details about the research.

This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. If you decide to join the study now, you can still change your mind later. You may stop at any time.

Any information you provide will be kept confidential. I will not use your personal information for any purposes outside of this research project. Also, I will not include your name or anything else that could identify you in the study reports.

Thank you in advance for your participation in the research!

Facebook Invitation

Invitation to participate in my research

Dear all,

My name is Suzan Awad and I am a doctoral student at Walden University and also a medical student. Therefore, I would like to kindly invite you to take part in my research study of understanding experiences and perceptions of patients with chronic diseases by investigating patients' views and perceptions of needs and priorities regarding Chronic Disease Management. The study will include a completion of a brief questionnaire of 20 simple questions regarding the management of your disease and a potential 30 to 40 minutes interview also regarding the management of your disease. Although all the participants of the study will complete the questionnaire, only few will be invited to participate to the interview and they will be notified in a timely manner.

I am inviting adults, aged at least 18 years old, with at least one chronic disease, who are also in the chronic or recovery phase of their diseases, regardless of age, gender or ethnicity. Example: a diabetic patient who has his/her disease under control and receives regularly insulin. The purpose of this study is to understand experiences and perceptions of patients with chronic diseases by investigating patients' views and perceptions of needs and priorities regarding Chronic Disease Management. Some more details and contact information:

You may take as much time as you need to decide to participate in the study and to ask any questions now or afterwards via phone or email [REDACTED] and suzan.awad@waldenu.edu). Please know that communication regarding this matter cannot occur via Facebook but only by phone or email. If you agree to participate, you will sign an informed consent form, which includes all the needed details about the research.

This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. If you decide to join the study now, you can still change your mind later. You may stop at any time.

Any information you provide will be kept confidential. I will not use your personal information for any purposes outside of this research project. Also, I will not include your name or anything else that could identify you in the study reports.

Thank you and I am looking forward to your reply!!!!

Consent Form

You are invited to take part in a research study of understanding experiences and perceptions of patients with chronic diseases by investigating patients' views and perceptions of needs and priorities regarding Chronic Disease Management (CDM). The study will include a completion of a brief questionnaire of 20 simple questions regarding the management of your disease and a potential 30 to 40 minutes interview also regarding the management of your disease. Although all the participants of the study will complete the questionnaire, only few will be invited to participate to the interview and they will be notified in a timely manner.

The researcher is inviting adults, aged at least 18 years old, with at least one chronic disease, who are also in the chronic or recovery phase of their diseases, regardless of age, gender or ethnicity. Example: a diabetic patient who has his/her disease under control and receives regularly insulin.

This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named Suzan Awad, who is a medical student and also a doctoral student at Walden University.

Background Information:

The purpose of this study is to understand experiences and perceptions of patients with chronic diseases by investigating patients' views and perceptions of needs and priorities regarding Chronic Disease Management (CDM).

Procedures:

- You may take as much time as you need to decide to participate in the study and to ask any questions now or afterwards, since this consent form includes phone numbers/email of the researcher as well as of Walden's representative. If you agree to participate, you can complete the brief survey now in a private area (e.g., in a private area of a nearby cafe, at your home, in a private area of church's lobby) but if you want to consider it, you can contact the researcher anytime you want to schedule a new meeting.

If you agree to be in this study, you will be asked to:

- Complete a brief questionnaire with 20 easy to answer questions and it will take you about 5 minutes to complete
- If you are selected, several days later you will be invited to participate to an interview regarding CDM which may also be conducted by phone. This interview will take about to 30 to 40 minutes. Please know that most individuals who complete the survey will not be interviewed and only very few individuals will be selected for the interview.

Here are some sample questions:

1. Over the past six months, when I received care for my chronic condition, I was asked for my ideas when we made a treatment plan:

None of the time, a little of my time, some of the time, most of the time or always?

2. Over the past six months, when I received care for my chronic condition, I was given choice about treatment to think about:

None of the time, a little of my time, some of the time, most of the time or always?

Voluntary Nature of the Study:

This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. If you decide to join the study now, you can still change your mind later. You may stop at any time.

Risks and Benefits of Being in the Study:

Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as fatigue or becoming upset. Being in this study would not pose risk to your safety or wellbeing. However, if you are dealing any kind of problem regarding this research please call the toll-free, 24-hour hotline of the Centers for Diseases Control and Prevention Lifeline at 1-800-273-TALK (1-800-273-8255); TTY: 1-800-799-4TTY (4889) to talk to a trained counselor.

Health care providers should acknowledge patients' experiences and individual difficulties regarding their chronic disease. The way that patients with chronic disease(s) understand and feel about health team behavior and actions can be considered as a great force for Social Change by promoting quality of patients' lives. By providing new insights into the matter and in depth understanding what patients have to say regarding the treatment of their disease(s), the present study will hopefully enable health professionals to acquire practical skills in Chronic Diseases Management and therefore to promote quality of patients' lives.

Payment: There is no payment for this study.

Privacy: Any information you provide will be kept confidential. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. Data will be kept secure by keeping them locked in a specific file cabinet and in computer protected by password. Data will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions: You may ask any questions you have now. Or if you have questions later, you may contact the researcher via phone or email [REDACTED] and suzan.awad@waldenu.edu). If you want to talk privately about your rights as a participant, you can call Dr. [REDACTED]. She is the Walden University representative who can discuss this with you. Her phone number is [REDACTED]. Walden University's approval number for this study is 07-30-13-0113381 and it expires on July 29, 2014. The researcher will give you a copy of this form to keep.

Statement of Consent: I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By signing below "I consent", I understand that I am agreeing to the terms described above.

Printed Name of Participant

Date of consent

Participant's Signature

Researcher's Signature

Authorization to Use or Disclose PHI for Research Purposes

The top portion of this form (above the dotted line) should be completed by the researcher. A copy of the form should be given to the research participant for his/her personal records.

Research Participant Name: Suzan Awad

Phone: [REDACTED]

Email Address: suzan.awad@walden.edu

Discloser of Information: Participant's name

Recipient of Information: Suzan Awad

Means of disclosing information (i.e., verbal, written, etc.): written and verbal

Information to be disclosed: Medical data (type and number of chronic disease(s))

Reason for the Release: This information is being released/obtained for the purpose of adequately assessing and investigating the perceived care for chronic conditions.

Authorization Provided by Research Participant:

I understand that this authorization permits the release of information between the two parties named above. I understand that I have the right to refuse to sign this release form. I understand that upon release, this information will be kept confidential; my identity will be concealed and data will not be re-disclosed outside of the specified individuals or agencies. I understand a photocopy of this release will be as effective as the original. I understand this authorization will be in effect for 12 months from the date signed unless cancelled by me in writing. Upon receipt of the written cancellation, this release will be void.

Signature

Date

(Signature of a Parent/Guardian if the person is under 18 or incompetent)

Witness

Date

Curriculum Vitae

Suzan Awad

SKILLS SUMMARY

- Bi-lingual in Arabic and English, both verbal and written
- Advanced skill level in Excel, Access, PowerPoint, Word and Internet Search
- Pending PhD degree in Public Health, with specialization in Epidemiology
- Proven ability to integrate clinical quality and service quality into all aspects of operations and establish a balance scorecard to monitor and evaluate progress and outcomes
- Establish positive collaborative working relationships with people at all organizational levels and across organizational boundaries
- Certified in Advanced Cardiovascular Life Support program (ACLS)
- Certified substitute teacher and para-professional in Illinois
- Proven to be calm under pressure, detail oriented and resourceful

EDUCATION

Walden University, PhD in Public Health Program Expected date of graduation February 2014	pending PhD
Windsor University School of Medicine pending Board Certification	MD degree
Walden University School of Business	MBA

VOLUNTEER EXPERIENCE

Leukemia and Lymphoma Association
 Staten Island University Hospital, IM nursing assistant
 Lutheran Hospital, IM nursing assistant