

QUALITY OF LIFE OF PERSONS WITH DIABETES: UNDERSTANDING THE
EFFECTS OF HEALTH LITERACY, SELF-EFFICACY AND KNOWLEDGE OF
CHRONIC ILLNESS AND DISABILITY

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ABSTRACT

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Livneh's (2001) quality-of-life-based model of psychosocial adaptation to chronic illness and disability (CID) provides a framework to conceptualize the process through which individuals negotiate challenges due to altered health. Drawing on this model, the current study examined the relationship between three process variables, health literacy, self-efficacy and knowledge of CID and quality of life outcomes among 126 individuals with diabetes. Four outcomes were studied, employment, physical and psychological well-being and social relationships. I hypothesized that these process variables predict quality of life. I also postulated that health literacy affects quality of life indirectly, through knowledge of CID and diabetes management self-efficacy. This study also investigated the prevalence of low health literacy in this population and tested whether health literacy skills are related to disparities in health outcomes based on race/ethnicity, socio-economic status (SES), and age.

Findings suggest that low health literacy is not prevalent in this group. Four in five (81.7%) individuals with diabetes have adequate health literacy. In examining whether health disparities in race/ethnicity, SES and age are reflected in health literacy scores, current findings support significant race/ethnicity effects on both reading and numeracy and on overall health literacy as well. There were no differences in health literacy scores based on SES and age. There was a lack of association between health literacy and the quality of life domains investigated. In terms of employment, individuals who worked, performed slightly

higher on the health literacy test, but the differences were not statistically significant. Results were different in relation to diabetes knowledge and diabetes management self-efficacy. Findings suggest an unadjusted effect of self-efficacy and diabetes knowledge on employment. In the adjusted model, physical health and the level of interference of diabetes with activities of daily living (ADLs) are the main statistically significant independent effects that explain the odds of one being employed. Although high levels of self-reported diabetes management self-efficacy is strongly associated with employment, the causal pathways for this relationship is likely to be through physical health and the lack of interference of diabetes with ADLs. In relation to physical health, the effect of diabetes management self-efficacy holds in the adjusted model as well, supporting the presence of an independent non-redundant effect. Level of understanding of diabetes and its treatment positively affects physical health. Results of regression analysis indicate that higher levels of diabetes management self-efficacy and a better understanding of diabetes and its treatment is associated with better psychological well-being and social relationships as well.

The structural and predictive utility of Livneh's model was partially supported by these findings. Empirical evidence from this research substantiates the relevance of diabetes management self-efficacy and the level of understanding of diabetes and its treatment on different quality of life domains. The current findings have applicability for vocational rehabilitation. This research evidence supports the importance to involve vocational rehabilitation customers who have diabetes in diabetes knowledge and self-efficacy training. Clinical interventions that teach factual knowledge and health management behaviors could help individuals improve their understanding of their medical condition and enhance self-efficacy, which in turn has benefits on several quality of life domains.

For Lea and Zsolt

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Chapter 1

Introduction

Health literacy, the ability to read, understand, and act on health information is linked to health outcomes. Low health literacy is prevalent in adults and has far reaching negative consequences for several indicators of health (Baker, 2006; Berkman et al., 2004; DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Lincoln et al., 2006; Sudore et al., 2006; Wolf, Gazmararian, & Baker, 2005). A systematic review of relevant articles published between 1980-2003 found that the odds of a poor outcome is 1.5 to 3 times higher for individuals with low health literacy (DeWalt et al., 2004). Adequate health literacy in turn is associated with better health outcomes (Carmona, 2006) in individuals with different disabilities and chronic conditions (Mancuso & Rincon, 2006; Weiss, Francis, Senf, Heist, & Hargraves, 2006). It is also believed, that health literacy has the potential to reduce health disparities by race, SES and educational attainment (Fiscella, Franks, Gold, & Clancy, 2000; Saha, 2006). Understanding and properly acting on health care information is important for effective chronic disease management. These competencies eventually lead to the maintenance or improvement of health.

While the general education level of the population never before has been this high (Cheeseman-Day & Newburger, 2002; Stoops, 2004), averaging for adult Americans at above high school level (Kirsch, Jungeblut, Jenkins, & Kolstad, 2002), many individuals struggle with low literacy and low health literacy. Two waves of large scale surveys found similar results in investigating adult literacy levels in the United States. The National Adult Literacy Survey (NALS), conducted in 1992 on a random representative sample of adults found that large proportions of the population have low or marginal literacy skills (Kirsch et al., 2002). Data indicates that about 40 million of American adults are functionally illiterate and 50 million have marginal literacy skills. Individuals with low literacy experience difficulties synthesizing and integrating information from lengthy texts or performing mathematical tasks, involving two or more sequential operations, which leads to challenges in daily functioning, particularly in tasks that involve problem solving (Kirsch et al., 2002).

The National Assessment of Adult Literacy (NAAL, 2003) as a follow-up to NALS, also found that many adults struggle due to low or moderate levels of literacy (Cutilli & Bennett, 2009; Kutner, Greenberg, Jin, & Paulsen, 2006). About one-third of survey participants have no more than basic literacy skills that permit only simple, everyday literacy tasks (Kutner et al., 2006). Low literacy is pervasive in spite of population-level average increase in formal education, suggesting a disconnect between the number of years of education attained and literacy skills.

Data on the state of health literacy is available from research studies involving smaller samples. These studies suggest that health literacy skills are comparable to general literacy skills. Large proportions of adults have low health literacy skills. Marginal or inadequate health literacy was found at 36-48% of the samples studied, with sample sizes ranging from

200 to 3,260 individuals (Baker, Parker, Williams, & Clark, 1998; Baker, Williams, Parker, Gazmararian, & Nurss, 1999; Baker et al., 2002, 2007). The prevalence and far reaching negative consequences of poor health literacy in adults alerted researchers to study this issue and remedy these gaps (Carmona, 2006).

Lower levels of health literacy impacts a broad spectrum of health behaviors, and ultimately health status. Poor health literacy was found to be associated with poor knowledge of disease, decreased likelihood for using preventive health care services, higher rates of hospitalization, more need for emergency care, less medication adherence, and worse health-management (Baker et al., 1998, 2002; Kripalani, Paasche-Orlow, Parker, & Saha, 2006). Low health literacy also creates communication barriers between the individual and the health care provider. Research suggests that patients with low health literacy encounter difficulties in communicating with health care personnel, and find it difficult to follow the doctor's instruction or interpret prescription labels (Davis et al., 2006; Houts et al., 1998; Houts, Witmer, Egeth, Loscalzo, & Zabora, 2001; Kripalani & Weiss, 2006; Parker & Gazmararian, 2003; Schillinger, Bindman, Wang, Stewart, & Piette, 2004; Sudore et al., 2009). Underlying mechanisms and connecting pathways between literacy and health outcomes are complex and not well understood, but studies have repeatedly found a direct link between health literacy and health outcomes.

Health literacy was found to be associated with certain demographic characteristics. Low levels of health literacy are more prevalent in minorities, older and less educated individuals, women, and individuals with low SES (Sudore et al., 2006). Studies on functional literacy skills found that socioeconomically disadvantaged individuals, members of certain racial/ethnic groups and the elderly are particularly at risk due to these limitations (Kirsch

et al., 2002). As far as general literacy skills, the NALS found that older adults were more likely to have limited literacy in comparison to other age groups. This survey also found that individuals at lower literacy level were more likely to receive food stamps than individuals at higher literacy level, and almost half of those at lowest literacy level live in poverty. In terms of race/ethnicity, the NALS found that all minorities perform lower on health literacy tests than the White majority. They also show disparities in health status when compared to the White majority (Kirsch et al., 2002).

Quality of life is "viewed as a broad and multidimensional construct that encompasses several life domains" (Livneh, 2002, p.154). Its core domains include psychological well-being, physical well-being, social and interpersonal well-being, financial and material well-being, employment or productivity and functional ability (Bishop, 2005). Livneh (2001) grouped these domains into three major areas of functioning, the intrapersonal (health, functional abilities, and psychological well-being), the interpersonal (functioning amongst family and peers) and the extrapersonal (aspects of functioning pertinent to learning, work, housing, and recreation).

The World Health Organization (WHO) defines quality of life as "individuals' perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (World Health Organization, 1998). WHO highlights the multidimensional nature of the construct, and distinguishes dimensions that include physical health, psychological and social well-being and environmental integration. Quality of life is the result of a subjective evaluation and it is contingent on one's culture and social milieu.

Health is a fundamental aspect of one's quality of life. Several studies investigated direct

and indirect pathways of health literacy to health outcomes in groups of individuals with various types of chronic illnesses (Berkman et al., 2004; DeWalt et al., 2004; Wolf et al., 2005). In contrast, the relationship of health literacy and employment outcome was less studied. To a limited extent, the National Adult Literacy Survey (Kirsch et al., 2002) gathered information on the socio-economic characteristics of the sample and explored the relationship of general literacy level and employment. It was found that individuals with higher level of literacy were more likely to be employed, worked more hours and had higher wages than individuals with lower literacy level.

There is a large body of literature on health literacy (Zorn, Allen, & Horowitz, 2004) especially in the medical field. Outcomes of a bibliometric analysis identified a dramatic increase in the number of studies exploring this topic in the past couple of decades (Bankson, 2009). Most publications were reported in the *Journal of General Internal Medicine*, *AIDS Education and Prevention*, *Journal of School Health*, *Patient Education and Counseling*, *Journal of Health Communication*, *Adult Learning*, *American Journal of Health Education*, *College Student Journal*, *Health Promotion International* and in the *American Journal of Health Behavior*. The lack of studies on this topic in the vocational rehabilitation literature suggests that there is a gap in existing research examining the association of health literacy with employment outcomes in people with chronic illness and disability.

The relationship of health literacy and work is an area of research with potential for new knowledge particularly in regard to the vocational rehabilitation field. The benefits of work on the well-being of the individual cannot be sufficiently stressed (Bishop, Chapin, & Miller, 2008; Marrone & Golowka, 1999). Employment is fundamental for societal integration and economic self-sufficiency. Work carries not only financial benefits, but also expands one's so-

cial networks (Marrone & Golowka, 1999). While several factors could potentially moderate the effects of unemployment (e.g., coping, hardiness, social support, education, or ethnicity, and the social, environmental or economic climate in which the individual lives), generally the lack of employment has adverse health and psychological effects (Dooley, Fielding, & Levi, 1996). An unemployed individual is at risk of developing unhealthy behaviors, such as alcohol consumption, or smoking, that may increase the risk of disease and mortality (Dooley, Catalano, & Hough, 1992). Unemployment more than doubles the risk of developing depression symptoms (Dooley, Catalano, & Wilson, 1994; Marrone & Golowka, 1999). It can be a major stressor leading to the loss of financial resources and psychosocial assets such as status, social support, meaning in life and time structure (Dooley et al., 1996). To study employment and factors that could influence employment outcomes is very important for individuals regardless of disability status.

Historically persons with disabilities had less opportunities for employment than persons without disabilities. The employment gap between person with and without disabilities persists in spite of improved vocational rehabilitation services (Erickson & Lee, 2008; Rehabilitation Research and Training Center, 2010). The 2010 Annual Disability Statistics Compendium, based on data gathered with the 2009 American Community Survey, reports that 12% of the U.S. population has a disability. In terms of employment, 74% of adults without disabilities are working (51% work full-time), but only 35% of persons with disabilities are employed, and only a small proportion of individuals with disabilities (20.0%) are working full-time (Rehabilitation Research and Training Center, 2010). There is a gap of 39% in employment between persons with and without disabilities. The majority of persons with disabilities are affected by unemployment. To decrease the gap between employment

outcomes of people with and without disabilities, more research is needed to identify determinants of employment, especially for persons with CID. Several studies investigated potential determinants of employment, but the associations between health literacy and employment outcomes and the underlying mechanisms connecting these constructs have not yet been explored in vocational rehabilitation research. Therefore, a study that investigates the connection and specific mechanisms relating health literacy to employment outcomes would be of benefit in understanding factors that influence employment outcomes for people with disabilities.

Adequate health literacy is particularly important for persons with disabilities, as large proportions of these people are expected to manage challenges that occur due to altered health or due to changes in the health care system. These individuals need to quickly identify first signs of changing health status and seek out appropriate resources to help remedy issues and properly adjust. For example some individuals with CID are often expected to follow a regular medical regimen (Baker, 1999). Many individuals with CID are in ongoing contact with health care providers and the health care system. Low health literacy carries the risk for poor self care and poor medical care. A better understanding of factors that impact quality of life outcomes could help design more interactive and effective rehabilitation interventions based on individualized self-management training to effectively maintain or potentially improve one's health status. Many disabilities and chronic conditions require ongoing self-care and lifestyle modification. Understanding factors that could impact successful adaptation to such changes is fundamental to improve the quality of life of these individuals.

The aim of this study is to explore the associations and mechanisms that underlie the

relationship between health literacy and quality of life outcomes. Of primary interest for this study is employment. Studying these relationships could help better understand the determinants of work in persons with CIDs. A better understanding of these issues could have major implications for employment outcomes for these individuals. Such knowledge could be used to design interventions for these individuals, particularly in regard to medical self-management and treatment planning. Furthermore, this study examines the relationship of health literacy with three other quality of life domains, psychological well-being, physical health and social functioning. These domains are also reflective of an individual's overall well-being. Increasing health literacy influences not only better self-management but also disease prevention, or stabilization of chronic conditions that in turn could increase the likelihood to retain or gain employment.

1.1 Statement of the Problem

Individuals who have the skills to understand and act upon health care information are more successful in negotiating the health care environment. Such skills lead to successful management of one's health, and ultimately improve one's physical well-being. Physical and emotional health, social functioning and employment are important domains of quality of life. Persons with different disabilities are expected to systematically manage their health, and being competent in accessing, processing and using health information is important for their functioning. Most prior research published predominantly in the medical field explored the relationship between health literacy and health outcomes. A large number of studies found that low literacy adversely affects health outcomes. It has been found that individuals with low health literacy have less medical knowledge, have difficulty understand-

ing basic health information, experience increased hospitalization and use of preventive care services (Carmona, 2006; Kripalani et al., 2006). Low health literacy ultimately leads to worse control of one's chronic condition (Kripalani et al., 2006).

Pathways between health literacy and employment outcomes have not been studied, yet they are highly likely to resemble the associations of health literacy with health outcomes. Similarly, health literacy and its connection to the psychological well-being and social functioning of individuals have been also studied to a limited extent. Work is an important aspect of an individual's life. Employment is very important for persons with chronic illness and disability. It enables individuals to access financial resources, and health benefits. Its psychological benefits cannot be sufficiently stressed. Historically persons with disabilities had significantly lower employment rates than persons without disabilities. Understanding variables that can influence and predict employment outcomes is very important and has major implication for the vocational aspects of these peoples lives.

The goal of this present study is to increase understanding of the relationship between health literacy and quality of life. This study examines pathways and associations between health literacy and employment outcomes. In addition it also explores the relationship among health literacy and psychological and social well-being. The current research will also examine associations between disability knowledge and self-efficacy and quality of life outcomes, and the impact of these constructs on direct associations between health literacy and quality of life outcomes. The study specifically tests whether these two constructs mediate the connection between health literacy and employment.

1.2 Conceptual Framework

This study is grounded in two conceptual models. The overall theoretical framework utilized to conceptualize the study draws on Livneh's model on psychosocial adaptation to CID (Livneh, 2001). In addition, for the purposes of this current study, a measurement model was created to illustrate the hypothesized relationships among the major constructs investigated.

1.2.1 Livneh's Model

Livneh's theoretical framework is a comprehensive conceptualization of the adaptation process that a person experiences when acquiring CID (Livneh, 2001). The model presents constructs that are typically involved in the adaptation process that unfolds as the person acquires a disability, and illustrates possible pathways and potential end results to this process. This quality-of-life based model of adaptation to the onset of CID, a simplified version of which is illustrated in Figure 1.1, describes the adaptation process that is contingent on specific factors and circumstances of the person, his/her environment and the type of disability or chronic condition. This model was slightly adapted to the purpose of current study.

The current study utilizes Livneh's model to illustrate the ongoing adaptation process that individuals with disabilities are experiencing while encountering challenges in their everyday life. For the purposes of current research, adjustment to onset of disability is replaced by adjustment to changes that are experienced due to altered health status or other life circumstances that directly impact the person's health. In the context of this research disability is already present and the individual is expected to successfully negotiate

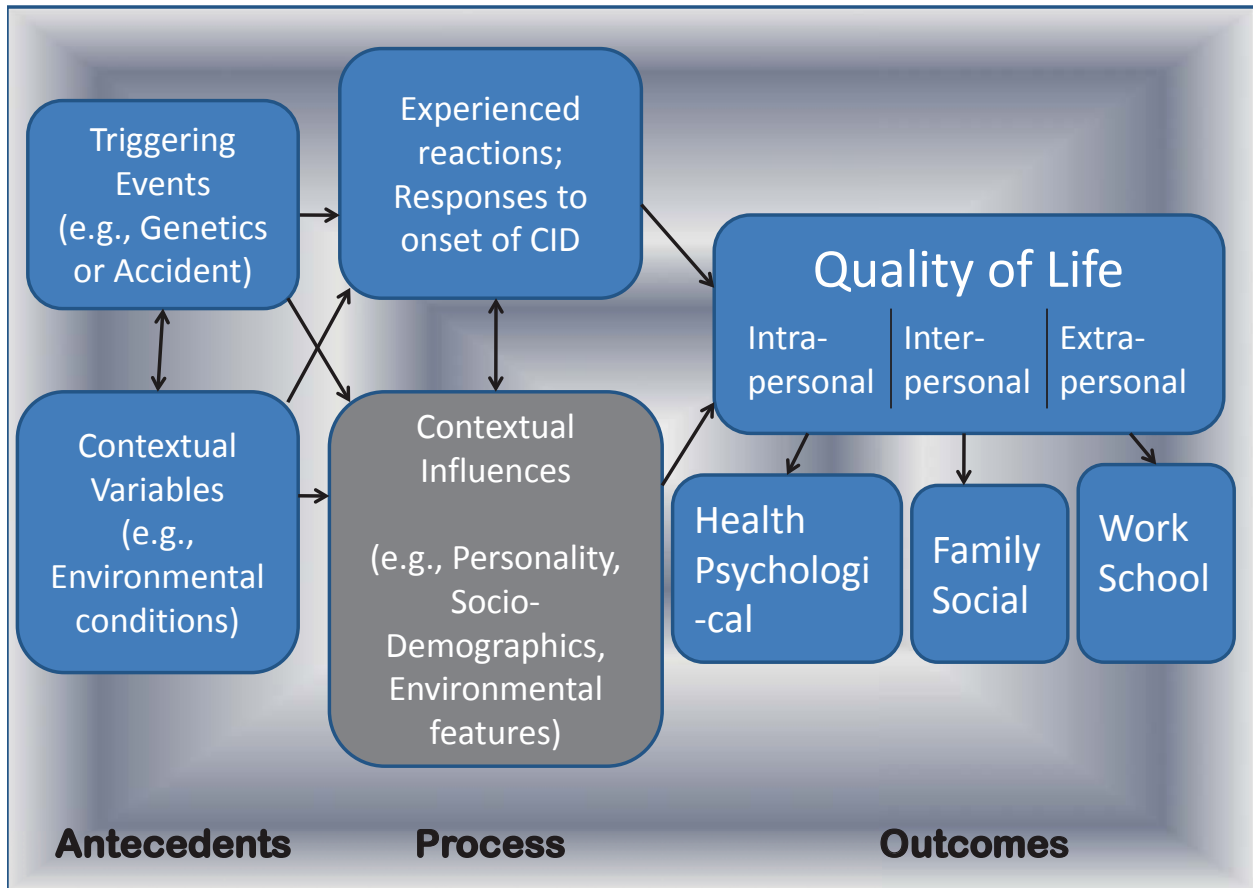


Figure 1.1: A Model Depicting the Structure, Content, and Process of Psychosocial Adaptation to CID (Livneh, 2001). For interpretation of the references to color in this and all other figures, the reader is referred to the electronic version of this dissertation.

changing health conditions to reverse, diminish or prevent adverse effects. In the context of this adjustment model, the main variable of interest to this study, health literacy, is a characteristic of the individual and encompasses functional health literacy knowledge and skills. This literacy level impacts quality of life outcomes and has both direct and indirect effect on these outcomes. Health literacy, as a knowledge and skills indicator, classifies under the group of variables that Livneh labels as *Contextual Influences*. With this group, health literacy, alongside general education level is grouped under *Sociodemographic Characteristics*. Knowledge of chronic condition and self-efficacy are hypothesized to have a mediator role in the relationship of health literacy and the outcome variables studied (i.e., employment, health

status, psychological well-being and social relationships). Knowledge of CID is also grouped under the *Sociodemographic Characteristics*. Self-efficacy, the other mediator studied, is a personality characteristic, and this variable is classified under the measures identified within the group of *Personality and Psychological Attributes*. In Livneh's model specific quality of life domains are presented as outcomes of adaptation. Quality of life has been studied prior by several researchers and identified as being the ultimate goal of rehabilitation (Crewe, 1980). In the current study four distinct outcomes are investigated. Of primary interest is employment, but physical, psychological well-being and social relationships are also examined in relation to the predictors studied.

1.2.2 Measurement Model

A measurement model was built to represent the postulated relationship of variables studied in this research (Figure 1.2). This model illustrates the hypothesized pathways that connect health literacy to the major quality of life outcomes, and includes both direct and indirect pathways that were planned to be investigated. In this model health literacy is the first component, and it is viewed as characteristic of the individual that will impact the effectiveness with which the person could manage his/her medical condition, through the management of health care information and his/her ability to navigate the health care system (Baker, 2006). Health literacy is also hypothesized to have an influence on other quality of life domains, such as employment, psychological well-being and social relationships.

Mediators represent another integral part of this model. Self-efficacy and knowledge of chronic condition are the two constructs that will be investigated within this category. In the context of this model, knowledge of chronic condition pertains to factual knowledge that

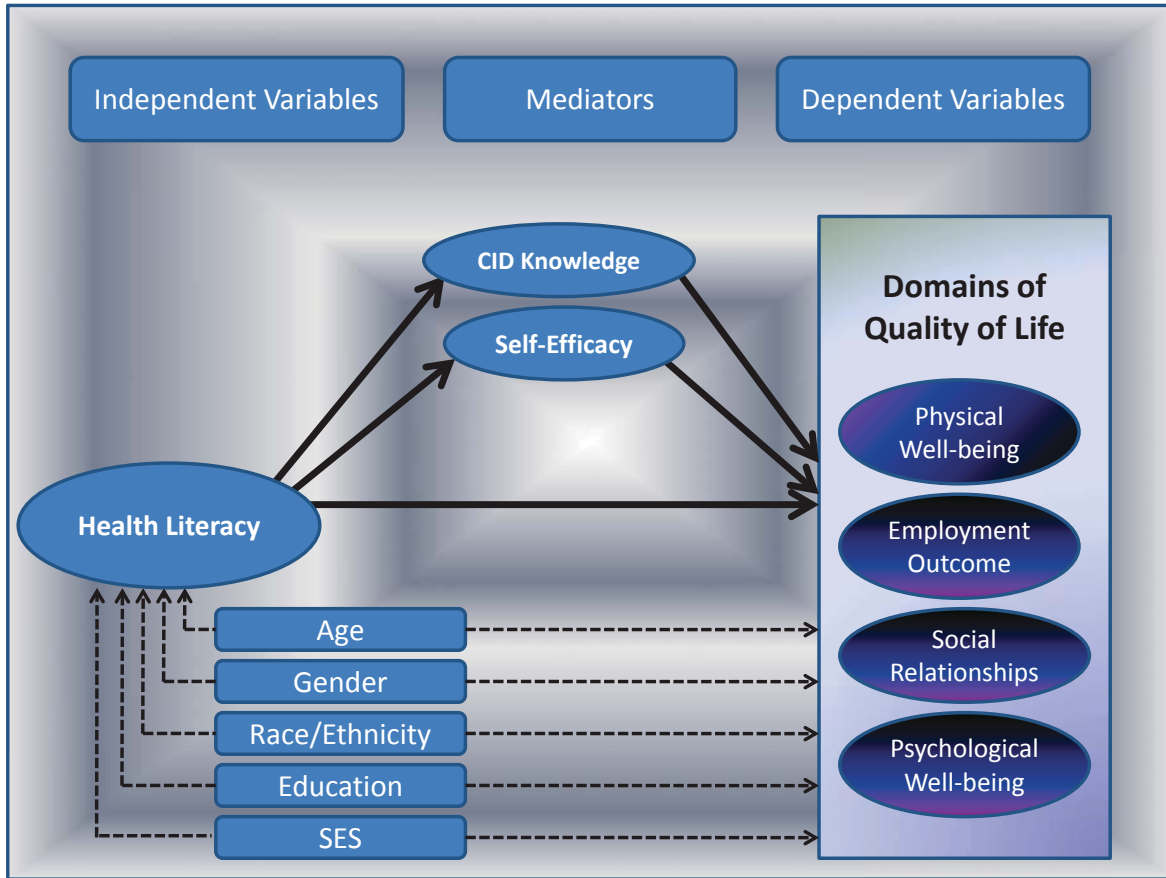


Figure 1.2: Conceptual Model of the Relationships Between Health Literacy and Quality of Life Outcomes

a person acquires about his/her disability or chronic condition. This specialized knowledge pertains to one’s disability. Acquisition of such knowledge enables the person to gather and be able to effectively utilize information that is pertinent to his/her health and well-being. The hypothesis in this model and in the relationship of the independent variable and this mediator can be conceptualized so that health literacy directly impacts quality of life outcomes, but also influences these outcomes indirectly, through factual knowledge pertinent to one’s disability, and through the individual’s self-efficacy. As illustrated in this measurement model, during analysis specific demographic characteristics will be accounted

for, as it has been found in prior studies that there are significant differences in health literacy in individuals of different age groups, educational level and of various racial/ethnic background (Kirsch et al., 2002). There are also disparities among individuals of different racial/ethnic backgrounds, age and SES on different outcomes as well (e.g., on health status or employment outcomes).

Two main pathways connecting health literacy to quality of life outcomes is illustrated in this measurement model. The first indicates direct effect of health literacy on the quality of life domains. A second pathway is illustrated through the mediated effects. In this relationship the effect of health literacy is assessed through the mediation of knowledge of CID and self-efficacy on quality-of-life outcomes. Both independent and combined mediational effects were planned to be tested during statistical analysis.

1.3 Purpose of the Study

The purpose of this study was to investigate the prevalence of low health literacy in individuals with diabetes, and to examine associations between health literacy and certain domains of quality of life. This study also examines the relationship between knowledge of CID and self-efficacy and quality of life. The outcome of main interest is vocational functioning. In addition, this study investigates the impact of health literacy on other important domains of quality of life, specifically health status, social relationships and psychological well-being.

Knowledge gained through this research could increase our understanding of health literacy and its associations to certain quality of life domains previously less studied. The most important addition will be in expanding knowledge of the relationship between health literacy and employment outcomes. Furthermore, this research could expand understand-

ing of the relationship of knowledge of CID, and self-efficacy with quality of life outcomes. These findings could add to efforts invested in understanding the discrepancy in employment outcomes of persons with and without disabilities. This knowledge could be used in practice settings to improve employment outcomes of persons with disabilities through the implementation of psychoeducational interventions aimed at improving self-management of one's disability or chronic condition. To exclude confounding effects due to unique characteristics of different disabilities, one group of persons with disabilities were recruited to participate, people with diabetes. This conditions is highly prevalent in the adult population and individuals with diabetes are expected to be constantly involved in the management of their chronic condition, lending this group to a suitable study population.

1.4 Research Questions and Research Hypotheses

1.4.1 Research Questions

The specific research questions that this research sought to answer include:

1. How prevalent is low health literacy in individuals with diabetes?
2. Are health literacy skills related to employment outcomes?
3. Are health literacy skills related to social functioning, psychological well-being and health status in this group of individuals with diabetes?
4. Are literacy skills related to disparities in health outcomes according to race/ethnicity, SES, or age?
5. How does knowledge of chronic conditions and self-efficacy influence specific domains of

quality of life (i.e., physical health, employment outcome, emotional and psychological well-being and social functioning) in people with diabetes?

6. What is the influence of knowledge of chronic conditions and self-efficacy on the relationship between health literacy and specific domains of quality of life (i.e., physical health, employment outcome, emotional and psychological well-being and social functioning)?

1.4.2 Research Hypotheses

Stemming from these questions the specific research hypotheses examined are the following:

Hypothesis 1: Direct effects

1. Health literacy has a direct positive effect on employment outcome.
2. Health literacy has a direct positive effect on social well-being.
3. Health literacy has a direct positive effect on psychological well-being.
4. Health literacy has a direct positive effect on physical well-being.

Hypothesis 2: Testing for knowledge of chronic condition as a mediator

1. Knowledge of chronic condition partially mediates the direct effect of health literacy on employment outcome.
2. Knowledge of chronic condition partially mediates the direct effect of health literacy on social well-being.

3. Knowledge of chronic condition partially mediates the direct effect of health literacy on psychological well-being.
4. Knowledge of chronic condition partially mediates the direct effect of health literacy on physical well-being.

Hypothesis 3: Testing for self-efficacy as a mediator

1. Self-efficacy partially mediates the direct effect of health literacy on employment outcome.
2. Self-efficacy partially mediates the direct effect of health literacy on social well-being.
3. Self-efficacy partially mediates the direct effect of health literacy on psychological well-being.
4. Self-efficacy partially mediates the direct effect of health literacy on physical well-being.

Hypothesis 4: Combined effects of knowledge of chronic condition and self-efficacy on the relationship of health literacy and quality of life outcomes

1. The combined mediation of self-efficacy and knowledge of chronic condition is stronger than their individual effects on the relationship between health literacy on employment outcome.
2. The combined mediation of self-efficacy and knowledge of chronic condition is stronger than their individual effects on the relationship between health literacy on social well-being.

3. The combined mediation of self-efficacy and knowledge of chronic condition is stronger than their individual effects on the relationship between health literacy on psychological well-being.
4. The combined mediation of self-efficacy and knowledge of chronic condition is stronger than their individual effects on the relationship between health literacy on physical well-being.

1.5 Definition of Terms

Quality of life is the outcome measure studied in this research. Of the several quality-of-life domains discussed in the literature (Bishop, 2005; Crewe, 1980; Livneh, 2001; World Health Organization, 1998) the current study investigated employment, psychological well-being, physical health and social relationships. The predictor of main interest is health literacy. Diabetes management self-efficacy and knowledge of chronic condition are predictors/mediators that were also studied in relation to the quality of life outcomes. The next sections provide definitions of these constructs.

Health literacy is a multifaceted and complex construct that currently has several conceptualizations (Baker, 2006). For the purpose of current research, health literacy was defined as the "degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Ratzan and Parker, 2000, p.vi). This is a widely adopted definition of health literacy. It has been used in studies conducted by the Institute of Medicine and the Department of Health and Human Services as well (Carmona, 2006; Department of Health and Human Services, 2000). Health literacy consist of skills and abilities that enable the individual to navigate the health sys-

tem, and is contingent on prior knowledge of vocabulary and conceptual knowledge of health and healthcare in particular (Baker, 2006). These skills include reading fluency, prose literacy (the ability to read and understand text), document literacy (the ability to locate and use information in documents), quantitative literacy (the ability to apply arithmetic operations and use numerical information in printed material) and is strongly contingent on prior knowledge of vocabulary (familiarity with individual meanings of words).

Quality of life is a multidimensional construct (Bishop, 2005; Crewe, 1980; Livneh, 2001; World Health Organization, 1998) that includes psychological or emotional well-being, physical well-being, social and interpersonal well-being, financial and material well-being, employment or productivity and functional ability (Bishop, 2005). For the purpose of this research, WHO's conceptualization of the construct is used (World Health Organization, 1998). According to this definition quality of life is the "individuals' perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (World Health Organization, 1998). Similarly to others, WHO also identifies distinct dimensions of quality-of-life that include physical health, psychological well-being and social relationships and environmental integration. Most importantly, quality of life is the result of a subjective evaluation and it is contingent on one's culture and social milieu.

In WHO's definition, descriptors of physical health include the lack of pain and discomfort, adequate energy and lack of fatigue, level of endurance, and the ability to control pain. The ability to maintain good physical health has a positive effect on one's quality of life. Psychological well-being means the presence of positive feelings, self-esteem, good cognitive functioning (thinking, memory, concentration and decision making ability), and a positive

body image. Positive emotions have a favorable influence on one's quality of life. The social relationships domain refers to personal relationships, sexual activity, and the amount and quality of social support received by the person. Optimal social functioning is fundamental for quality of life. Lastly, the environment domain describes physical safety and security, home environment, financial resources, health and social care, opportunities to acquire new information and skills, participation in recreation and leisure, exposure to pollution and noise, and the quality traffic and transportation experienced by the person. The better these conditions are, the higher one's quality of life is likely to be.

Self-efficacy is a psychological construct introduced by Bandura (1977). Self-efficacy denotes the individual's confidence in his/her skills and abilities to purposefully execute specific behaviors in order to be able to reach specific goals (Bandura, 1977). Self-efficacy in the health context is the individual's confidence in own abilities and skills to reach desired health outcomes. It identifies the person's confidence to perform behaviors such as medication adherence, compliance with treatment plan, certain regimens of diet, exercise or preventive behaviors (Sarkar, Fisher, & Schillinger, 2006).

Knowledge of chronic conditions denotes the factual knowledge a person acquires pertinent to his/her condition, and it is unique to each condition (Gazmararian, Williams, Peel, & Baker, 2003; Williams, Baker, Parker, & Nurss, 1998). This specialized knowledge pertaining to one's own disability enables the person to gather and utilize information that is relevant to his/her condition.

Chapter 2

Literature Review

First mentioned in 1974 in a paper titled *Health Education as Social Policy* (Ratzan & Parker, 2000), health literacy became the focus of intense research in the past decades, particularly in the medical field. Health literacy was studied in relation to several indicators of health. Studies have found that reading ability and numeracy in the health context and patient physical and psychological well-being are significantly related. This section of the paper provides an analysis of influential studies that were conducted to explore the nature of these relationships and underlying mechanisms.

This chapter begins with a discussion of theoretical and operational definitions of health literacy. Subsequent sections will cover knowledge of CID and self-efficacy, the other two predictors of main interest to this research. Seminal research investigating the relationships among knowledge of chronic conditions, self-efficacy and health literacy with the quality of life outcomes of focus to this study will be discussed next. The selection of this population was not a random choice, and the literature review will present the rationale for that as well.

2.1 Understanding Health Literacy

2.1.1 Definitions and Prevalence of Health Literacy

General Literacy Defined

The expert panel which convened to design the National Adult Literacy Survey, defined general literacy as the ability to use "print and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential" (Kirsch, Jungeblut, Jenkins, and Kolstad, 2002, p.2). To measure the construct, the NALS Committee developed three scales specifically to assess prose (ability to read and comprehend textual information), document (ability to read documents) and quantitative literacy (ability to perform arithmetic operations). This definition is independent of context, and pertains to generic written and numerical information processing skills.

Health Literacy Defined

Research on the topic of health literacy increased dramatically in the past decades. As a byproduct of this, as Baker (2006), a prominent researcher of this topic noted, significant confusion and debates occurred about its definition. There are several definitions of health literacy currently available but there is a lack of agreed upon definition of the construct (Baker, 2006). Issues with definition led to disagreement regarding its measurement (Baker, 2006).

The most widely accepted definition of health literacy comes from the introduction section of the *Current Bibliographies in Medicine* series published on health literacy (Ratzan & Parker, 2000). According to this definition health literacy is the "degree to which individuals have the capacity to obtain, process, and understand basic health information and services

needed to make appropriate health decisions” (Ratzan and Parker, 2000, p.vi.). Other major agencies and institutions also adopted this definition. It was used by the Institute of Medicine, in the *Health Literacy: A Prescription to End Confusion* report on health literacy and in several projects completed through the Department of Health and Human Services *Healthy People 2010* (Carmona, 2006; Department of Health and Human Services, 2000).

According to the most circulated definition currently available, health literacy is conceptualized as an individual capacity. It represents a combination of cognitive skills needed to perform basic reading and numerical tasks, that ultimately enables the individual to efficiently navigate the health care environment. This set of individual capacities include reading fluency, the ability to read and understand text (prose literacy), the ability to locate and use information in documents (document literacy) and the ability to apply arithmetic operations and use numerical information in printed material (quantitative literacy). Health literacy relies on prior knowledge of vocabulary (knowing what individual words mean) and on the conceptual knowledge of health and health care in particular (Baker, 2006).

A more comprehensive conceptualization of the construct identifies three types of health literacy (Nutbeam, 2000). Functional literacy is described as reading skills that enable an individual for effective daily functioning. Communicative or interactive literacy describes the ability to understand and extract information communicated orally through interactions with others and applying this information to new situations. Critical literacy is the individual’s ability to critically analyze the information that is used to have greater control over life events and situations (Nutbeam, 2000). This definition goes beyond functional literacy skills, and incorporates communication and critical thinking skills. All these conceptualizations delimit health literacy to individual capacity.

Other conceptualizations of the construct incorporate factors external to the individual. In this sense health literacy depends on both the characteristics of the person and the health care system. Health literacy may vary based on the medical problem, the health care provider and based on the system providing the care. One approach (Adkins & Corus, 2009) for example, using a sociocultural perspective, provides a multifaceted and complex view of health literacy. Health literacy in this context is defined as "the ability to derive meaning from different forms of communication by using a variety of skills to accomplish health-related objectives" (Adkins and Corus, 2009, p.202). Thus health literacy becomes rather a public act than a individual act, primarily because incorporates skills and competencies that assist people in navigating the social milieu. These researchers argue that communication, negotiation, interactions between the patient and the environment, and the ability of the person to successfully navigate the healthcare system requires more than cognitive abilities of decoding, processing and effectively using health information.

An expert panel from the Institute of Medicine concluded that health literacy is an achieved level of knowledge or proficiency that depends upon an individual's capacity and motivation to learn and also on the resources provided by the health care system. It encompasses cultural and conceptual knowledge, oral literacy (including speaking and listening skills), print literacy (including writing and reading skills) and numeracy. Literacy in the health context has three basic functions, that include obtaining health information and services, processing and understanding health information and making appropriate health decisions. Health literacy reaches beyond the individual's cognitive capacity, being rather socially constructed between the patient and the provider (Adkins & Corus, 2009).

Low literacy is prevalent among American adults. The 1993 Adult Literacy Survey

identified that large proportions of American adults have low reading skills, that impair their ability to function well in their everyday life (Kirsch et al., 2002). This study found that 90 million American adults have marginal or lower level of health literacy, placing them at high risk of being able to successfully negotiate the health care environment. Functional health literacy may be significantly worse, because this skill is context specific.

Low health literacy is also highly prevalent in the adult population of the U.S. As reported in previous research, 36-48% of the samples studied were identified as having marginal or inadequate health literacy (Baker et al., 1998, 1999, 2002).

Disparities in general literacy and health literacy skills exist based on socioeconomic status, age and racial/ethnic background. Low literacy is more prevalent in older individuals. Almost half (44%) of the 65 and older age group has low literacy. Low literacy is also more prevalent in minorities, females, individuals with less education and lower SES (Kirsch et al., 2002). The National Adult Literacy Survey found that African Americans, Native Americans and Hispanic Americans were overrepresented at low or marginal literacy level. There are disparities in health literacy among different racial/ethnic and age groups, and similarly health and health care disparities among these groups (Fiscella et al., 2000). A study indicated that reducing disparities in health literacy could possibly reduce disparities noted in health status among these groups (Saha, 2006).

2.1.2 Quantifying Health Literacy

Currently there are several conceptualizations of the health literacy construct. At one end there is functional health literacy involving a set of cognitive skills and at the other extreme health literacy is viewed as a social construct that transcends cognitive skills and include

social networking or characteristics of the healthcare system. Most studies investigated functional health literacy, primarily due to the lack of availability of a measure for the broader construct of health literacy (DeWalt & Pignone, 2005). There are several measures developed to quantify health literacy (Baker, 2006). Currently the most commonly used tests are the Test of Functional Health Literacy in Adults Short Form (Baker et al., 1999) and the Rapid Estimate of Adult Literacy in Medicine (Davis et al., 1993). These instruments have good psychometric properties and as a result many studies used them to operationalize functional health literacy.

The Rapid Estimate of Adult Literacy in Medicine (REALM) is the most common objective measure of adult literacy in medical settings. It is a valid and reliable instrument that measures reading ability. The full-scale REALM consists of 66-items. This test requires individuals to read and pronounce various medical terms and conditions in a three- to five-minute time frame. The number of correct pronunciations forms the basis of this assessment. Depending on scores attained, individuals are classified into four groups, that include: 1. third grade level or less, 2. four through six grade level, 3. seven or eight grade level and 4. nine grade level or above. Individuals at six grade level or below have inadequate literacy, those at seven or eight grade level have marginal literacy and the ones at high school or higher reading level have adequate health literacy. REALM has a short form as well, The Rapid Estimate of Adult Literacy in Medicine-Revised the REALM-R (Bass, Wilson, & Griffith, 2003). This is a brief, 8-item measure that has high internal consistency (Cronbach's alpha of 0.91).

The Test of Functional Health literacy in Adults (TOFHLA) is a sentence completion test based on the cloze procedure where individuals are asked to add missing words to sentences

from a list of options. The full-format of this test takes below 22 minutes to complete. This test measures comprehension of prose and numerical information. The TOFHLA consists a total of sixty-seven items, of which 17 are numeracy and 50 are reading comprehension questions. Individuals are grouped into inadequate, marginal, or adequate literacy level. Recently a shorter version of this instrument, the Short Test of Functional Health literacy in Adults (S-TOFHLA) was developed (Baker et al., 1999). This version consists of 36 reading comprehension items and 4 numeracy items and takes less than 12 minutes to complete. Just as in the long version, here as well individuals are grouped into three levels of health literacy, inadequate, marginal and adequate level of health literacy.

The Spearman correlation between REALM and TOFHLA is high ($r=0.80$, Baker, 2006) and both measures are highly correlated with general vocabulary tests (e.g., Wide Range Achievement Test).

Health Activities Literacy Scale (HALS) is a newer instrument that was developed by the Educational Testing Services (Baker, 2006). This instrument is considered more comprehensive than either the REALM or the TOFHLA. It includes items that measure prose, quantitative and document literacy. Literacy skills are measured in regard to five health-related areas (health promotion, health protection, disease prevention, health care, health maintenance and systems navigation).

Subjective assessments of health literacy were also used in some studies, where the physician's perception of patient's literacy level was used as an indication of the client's health literacy level.

The 2003 National Assessment of Adult Literacy survey included items with health content to measure the ability to purposefully use information related to health care. The items

were designed to fit the general literacy assessments such as prose literacy (i.e., skills to search and comprehend organized texts), document literacy (i.e., skills to search and comprehend noncontinuous texts in various formats), and quantitative literacy (i.e., skills to perform numeric computations of numbers embedded in printed materials).

2.2 Health Literacy, Health Outcomes and Psychosocial Well-being

There are both direct and indirect relationships between health literacy, health outcomes and psychological well-being. While several studies have found empirical support for the direct link between literacy, education, health literacy and health status, researchers still struggle to understand the indirect connections among these constructs (Baker, 1999). Understanding these mechanisms is fundamental to impact patient outcomes. The examination of factors that intervene between literacy and quality of life outcomes to mediate or moderate these relations represent topics of future research.

Health literacy was found to be related to health status, participation in preventive care and health promotion, frequency of hospitalization, the use of emergency care, adherence to treatment plan, illness complications and time to recovery (Baker et al., 1998, 2002; Kalichman, Ramachandran, & Catz, 1999). Low health literacy is linked to adverse health outcomes (Berkman et al., 2004; Wolf et al., 2005). Research found that individuals with low health literacy have less medical knowledge, have difficulty understanding basic health information, have worse treatment compliance, and do not benefit as much from preventive care services (Carmona, 2006; Kripalani et al., 2006) as do individuals who have adequate

literacy skills. Low health literacy is associated with worse control of one's chronic condition (Kripalani et al., 2006). A study showed that low health literacy is associated with higher prevalence of certain chronic conditions such as diabetes mellitus and heart failure (Wolf et al., 2005).

Significant associations were found between several health status indices and literacy level. Patients with inadequate literacy were more likely to be hospitalized than patients with adequate literacy after adjusting for age, gender, race, self-reported health, socioeconomic status, and health insurance (Baker et al., 1998). This study, based on a sample of 958 individuals using logistic regression found that the odds of being hospitalized was two times higher for individuals with low literacy. The adjusted odds ratio was 1.69 after controlling for demographic measures, health insurance and self-reported general health status in the month prior to enrollment in the study (Baker et al., 1998).

A study examining the effect of health literacy on mortality, found that inadequate health literacy is a significant predictor of all-cause mortality among community-dwelling elderly persons. The hazard ratios for all-cause mortality, after adjusting for demographics, socioeconomic status, and baseline health, were 1.52 and 1.13 for participants with inadequate and marginal health literacy, respectively, in comparison to participants with adequate health literacy (Baker et al., 2007).

Other studies examined health literacy in relation to treatment adherence. One study involving a sample of 117 HIV patients found that in the first year after enrollment into the treatment program 71% of the sample missed at least one dose (Golin et al., 2002). Among reasons why doses were missed 15% said this was due to too many pills and 8% said they were confused about instructions on dosage. Surprisingly, this study found no bivariate

associations between health literacy and treatment adherence. Another study on adherence to HIV treatment found that there is a significant association between health literacy, education and treatment follow-through (Kalichman et al., 1999). Results of multiple logistic regression indicated a significant and independent association between treatment adherence and literacy with control for age, ethnicity, income, HIV symptoms, substance abuse, social support, emotional distress, and attitudes toward primary care providers. Patients with low literacy missed doses for reasons that include confusion and depression. Health literacy was also a significant predictor of good glycemic control, with an odds ratio (OR) of 3.97 in a sample of persons with diabetes (Schillinger et al., 2003).

A study investigating the relationship between health literacy and functional health status in a sample of 2,923 community-dwelling older adults found that inadequate health literacy adversely affects physical function and mental health (Wolf et al., 2005). Chronic conditions, health risk behaviors, and sociodemographic characteristics were accounted for in the regression model. Results suggest that inadequate health literacy increases the odds of experiencing challenges with activities of daily living (OR=2.83) and pain that interferes with normal work activities (OR=2.01). These individuals also more likely report on activity limitations due to physical health (OR=1.79). This study confirmed the associations between health literacy and poor general health.

Studies on health literacy and its relationship to mental health found that low literacy is associated with depression (Gazmararian, Baker, Parker, & Blazer, 2000). Individuals with inadequate health literacy had 2.7 times the odds of being depressed in comparison to individuals with adequate health literacy. However, after adjusting for demographics, health status measures, social support, and health behaviors, the computed odds ratio was smaller

and not statistically significant. Another study, investigating the relationship of literacy and emotional well-being, found a that lower health literacy was associated with elevated depression and poorer social support (Kalichman & Rompa, 2000).

Evidently, many of this studies point toward the significant association between health literacy and health outcomes. People who have the skills to read, comprehend and act on health information, have better health outcomes than individuals who have limitations in these skills. But the relationships are not always straightforward. Other variables, such as disease knowledge and self-efficacy can intervene in between literacy and outcome. More exactly, as some studies suggest, health literacy could manifest its impact indirectly, through knowledge of one's condition and self-efficacy.

2.3 Self-Efficacy, Knowledge of Chronic Condition and Health Literacy

Self-efficacy is defined as one's belief in own abilities to carry out tasks to reach specific goals (Bandura, 1977). According to Bandura, these expectations of personal mastery affect both initiation and persistence of coping behavior. "The strength of people's convictions in their own effectiveness is likely to affect whether they will even try to cope with given situations" (Bandura, 1977, p.193). Self-efficacy has been studied extensively regarding health-related behavior.

Self-efficacy is situation and task-specific (van der Bilj, van Poelgeest-Eeltink, & Shortridge-Baggett, 1999). Individuals can feel efficacious in one situation, but less efficacious in a different situation. Individuals with diabetes for example perform specific self-management

tasks such as eating an appropriate diet, getting proper exercise, checking ones blood glucose levels, taking oral medications and/or insulin, and, often, balancing the amount of medication or insulin respective to the amount of food intake, amount of exercise, and varying blood glucose levels on a daily basis (Wallston, Rothman, & Cherrington, 2007). Behaviors required for diabetes management differ significantly from behaviors needed to manage other disabilities and chronic conditions.

Self-efficacy is important in initiating and sustaining actions, and as such it has major relevance in several aspects of human behavior, including health-promoting behaviors in individuals with different disabilities and chronic conditions (Allegrante & Marks, 2003; Johnson et al., 2006; Nakahara et al., 2006; Sarkar et al., 2006). These behaviors include several aspects of the treatment plan, from changing one's lifestyle (diet, exercise), to more treatment-specific self-care (such as glucose management, or taking one's medication) in the case of persons with diabetes. Self-efficacy influences health-related goals and choices, and the amount of effort invested in attaining goals (Wallston et al., 2007). Ultimately, self-efficacy influences health outcomes. A review of studies on self-efficacy and diabetes found that it was associated with successful management of diabetes (Wallston et al., 2007). Another study (Johnson et al., 2006) found that self-efficacy mediated the relationship between providers and medication adherence. More positive interactions foster adherence self-efficacy (the belief that one can follow a treatment regimen) which ultimately affected adherence to medication in a sample of HIV infected patients.

An examination of the causal relationship between psychosocial factors and glycemic control in a group of diabetic patients at baseline, 6 months and 12 months following baseline found that self-efficacy directly reinforced adherence, and adherence was associated with

glycemic control (Nakahara et al., 2006). This study also showed that self-efficacy is a mediator of psychosocial variables on glycemic control (psychosocial factors examined included social support and self-efficacy). Nakahara's study, involving a structural equation modeling analysis, showed that self-efficacy has both direct and indirect effect on glycemic control in patients with diabetes. An earlier study also showed through multiple regression analysis that self-efficacy is associated of diabetes self-care behavior (Glasgow et al., 1989). What this study also found was that self-efficacy differed respective to the specific area of self-care. Efficacy in adherence to a specific diet or a physical exercise program was lower that for medication adherence or glucose testing.

A study of the relationship of self-efficacy and self management behaviors in a sample of individuals who have diabetes found a significant association between self-efficacy scores and self-management behaviors such as diet, exercise and foot care, but found no associations between self-efficacy and medication adherence (Sarkar et al., 2006). This study also found, that adjustment of health literacy scores have no impact on the relationship between self-efficacy and self-management, which led the researchers conclude that self-management interventions based on self-efficacy could be effective with groups of different health literacy levels.

Another study on a group of individuals with osteoarthritis found that self-efficacy is relevant in the management of the condition, and impacts one's general well-being and health status by acting as an important mediator of arthritis-related outcomes (Allegrante & Marks, 2003).

Health literacy is related to one's knowledge of chronic condition. Knowledge of chronic illness and disability pertains to the factual knowledge and individual acquires regarding the

conditions. There are instruments available to measure conceptual disease-specific knowledge (e.g., asthma, hypertension, diabetes, and heart failure) but there is no current measure of the general public's conceptual knowledge about health and illness (Baker, 2006).

A study on 653 Medicare managed care enrollees found that levels of chronic disease knowledge were low, even for participants with adequate literacy (Gazmararian et al., 2003). Specifically, this study found that patients with inadequate health literacy were less likely to correctly answer 8 of the 20 asthma questions, 5 of the 11 diabetes questions, 4 of the 16 heart failure questions, and 8 of the 25 hypertension questions than those with adequate literacy skills (Gazmararian et al., 2003). In the group of individuals who have diabetes, smaller proportion knew the role of medication in regulating their blood sugar in comparison to those with adequate literacy (50% respectively 68%). There was a direct correlation between mean knowledge scores and literacy levels. Furthermore, at multivariate analysis this study found that health literacy had a significant association with chronic disease knowledge after controlling for demographic variables, disease duration, and prior educational exposure to information about the chronic disease (Gazmararian et al., 2003). This study concludes, that poor health literacy is related to poor knowledge of chronic illness and disability.

An earlier study involving participants with hypertension and diabetes also found that individuals with low health literacy are less likely than patients with adequate literacy to know essential information about their chronic condition (Williams et al., 1998). In this study there was a strong correlation between functional health literacy and patients' knowledge of their illness. Patients with diabetes and hypertension with low health literacy answered correctly fewer knowledge questions, than patients with adequate health literacy. This study specifically found that while only 50% of those with inadequate literacy knew the symptoms

of hypoglycemia, 94% of those with adequate functional health literacy knew those symptoms (Williams et al., 1998). Findings also showed, while 92% of patients with hypertension and adequate literacy levels knew that a blood pressure reading of 160/100 millimeters of mercury (mmHg) was high, only 55% of those in the lowest reading level were aware of that. Chronic disease knowledge is related to demographic measures such as age, gender, education, and race (Gazmararian et al., 2003).

Another study examining both the effect of self-efficacy and chronic disease knowledge, investigating the impact of health literacy on longitudinal asthma outcomes found a statistically significant relationship between low health literacy and worse quality of life, worse physical function, and more emergency department utilization (Mancuso & Rincon, 2006). When examining the effect of literacy in the context of other variables, health literacy did not remain statistically significant in predicting quality of life. Although the magnitude of its effect on emergency department utilization remained the same as in bivariate analysis, its effects on quality of life and functional status became attenuated when demographic characteristics, such as age and education were entered in the analysis. This study found that disability severity and self-efficacy did not change the effect of literacy on outcomes, but when asthma knowledge was introduced, there were significant changes in health literacy regression coefficients (Mancuso & Rincon, 2006). The study also found that patients with low literacy had less asthma-related health knowledge. Unlike other studies, that showed a link between self-efficacy and client outcomes, this study found no relationship between health literacy and self-efficacy, but detected an association between health literacy and asthma-knowledge.

Understanding the mechanisms through which self-efficacy and chronic disease knowledge

can influence these different quality of life outcomes and its relationship to health literacy is very important for self-care, health management and ongoing monitoring of one's functional status, as that is expected of persons with many types of CIDs. The hypothesized relationship of this study states that health literacy affects quality-of-life outcomes directly, but also indirectly through self-efficacy and chronic disease knowledge. Health-literacy influences one's level of self-efficacy, the belief that one can cause a desired outcome and these together positively impact desired quality-of-life outcomes. Similarly, health literacy also acts indirectly on outcomes through the effect on chronic disease knowledge. Previous paragraphs presented studies that examined direct and indirect pathways from literacy and health outcomes. This study aims at examining the relationship of this variable on other quality of life outcomes. The primary focus is on employment, but the relationship to psychological well-being and social functioning will also be examined during this study.

2.4 Narrowing the Focus to Diabetes

Diabetes represent a major public health concern. The literature has noted that there is an emerging "diabetes epidemic" internationally (Wild, Roglic, Green, Sicree, & King, 2004). The constant need for care and the costs involved with diabetes increasingly urge researchers, healthcare providers and policy makers to invest more in better understanding the condition in order to prevent or more effectively treat it (American Diabetes Association, 2008; Centers for Disease Control and Prevention, 2008). In the United States in 2007 the estimated direct and indirect cost combined spent on diabetes was 174 billion dollars (Centers for Disease Control and Prevention, 2008).

Diabetes Mellitus is a chronic condition characterized by high levels of blood glucose

(sugar) that results from deficits in insulin production, insulin action or a combination of these two (Hornichter, 1995). There are two major types of diabetes, type 1 or juvenile-onset and type 2 or adult-onset diabetes.

Persons living with type 1 or juvenile-onset diabetes cannot produce insulin in the body. In this condition the body's immune system destroys the beta cells of the pancreas. These cells are responsible for insulin production. As a result the body cannot produce the insulin, resulting in a deficit in the metabolism of sugar (Centers for Disease Control and Prevention, 2008). This type is also known as insulin-dependent diabetes. The person has to inject insulin into his/her system regularly to ensure normal metabolism of glucose. This type of diabetes typically occurs in early childhood, but may occur at any age. As many as 5-10% of all diabetes cases are of this type (Centers for Disease Control and Prevention, 2008). There are certain risk factors that may lead to this condition, but the mechanisms of why and how it develops are still not well understood (Centers for Disease Control and Prevention, 2008).

In non-insulin dependent or type 2 diabetes, which occurs in 90-95% of cases, the body develops insulin resistance. The body cells cannot efficiently use insulin, as a result excess sugar accumulates in the body. What typically happens as the disease unfolds, is that the body needs more insulin and the pancreas fails to produce the right amount (Centers for Disease Control and Prevention, 2008). There are certain risk factors that contribute to the development of this condition, that include age, race-ethnicity, obesity, genetics or family history, deficient glucose metabolism and lack of physical activity. Type 2 diabetes occurs in adulthood, and is disproportionately high in older adults. This condition is less likely to occur in young children or adolescents. In individuals with signs of prediabetes, the development of type 2 diabetes is preventable, especially with lifestyle interventions (Centers

for Disease Control and Prevention, 2008).

A more rare form of diabetes is gestational diabetes, that occurs in some pregnant women and manifests in glucose intolerance. There are other rare types of diabetes as well, that have similar symptoms and may lead to further complications if not properly treated (Centers for Disease Control and Prevention, 2008).

Diabetes is a highly prevalent chronic condition in the United States and internationally (Centers for Disease Control and Prevention, 2008; Wylie-Rosett, 2009) and the prevalence of this condition will likely increase in the following decades (Wild et al., 2004). A recent study on the global prevalence of diabetes using data from year 2000 to project the prevalence of the condition for year 2030, suggest that during these decades diabetes will double across the globe. These computations were extrapolated on 191 countries that are members of the World Health Organization using data from certain countries and the United Nations population estimates (Wild et al., 2004).

The prevalence of diabetes is correlated with age (Cowie et al., 2010). Higher rates of older individuals have diabetes, and the 65 or older age group report the highest rates of diabetes. Approximately 20% of older adults report having diabetes, and only three percent of the 18-44 age bracket have the condition (Centers for Disease Control and Prevention, 2009; Cowie et al., 2010). The prevalence of diabetes is disproportionately higher in older adults in comparison to individuals of other age categories. As far as health literacy skills, a study found that individuals with low health literacy are more likely to report having diabetes (Wolf et al., 2005).

Studies also have found that diabetes is higher in certain racial-ethnic groups (Cowie et al., 2010). This study in particular found that the prevalence of diabetes is more than two

times as high as in non-Hispanic African Americans and Mexican Americans than in individuals of Non-Hispanic White racial/ethnic background. Type 2 diabetes is more prevalent in the ethnic minorities including Non-Hispanic African Americans, Hispanic/Latino Americans, Asian Americans, and Native Americans, and Native Hawaiians and Other Pacific Islander groups than it is in Non-Hispanic White Americans (Centers for Disease Control and Prevention, 2008). In terms of health outcomes of persons with diabetes, it was found that African American individuals are more likely than European Americans to experience poor long term diabetic outcomes such as diabetic retinopathy, amputations, and kidney disease (Sequist et al., 2008).

Within the last decades diabetes become a major cause of morbidity and mortality in the United States (Fowler, 2010). Data collected by the Center of Disease Control and Prevention based on the examination of 72,507 death certificates found that diabetes was identified as the seventh leading cause of deaths in the United States in 2006 (Centers for Disease Control and Prevention, 2008). Diabetes, as a major cause of mortality is presumably higher than what was reported actually (for less than half of deceased individuals is diabetes mentioned in the death certificate, CDC, 2008).

The results of the 2004-2006 National Health Interview Survey (NHIS) indicate that nearly 24 million people in the United States have diabetes. Based on the most recent data available from the National Center for Health Statistics (NCHS), collected with the National Health Interview Survey, 1997-2009, the prevalence of diabetes doubled between 1997 and 2009 among adults aged 18 or older, from 5.1% in 1997 to 10.1% in early 2009 (Centers for Disease Control and Prevention, 2009). From 2008 to 2009, in only one year the rate of diabetes increased from an estimate of 8.2% to 10.1% in adults 18 or older. An examina-

tion of estimates of diagnosed and undiagnosed diabetes combined reach significantly higher numbers. As many as 23.6 million people or 7.8% of the population have diabetes, with 5.7 million undiagnosed individuals (Centers for Disease Control and Prevention, 2008).

A study investigating global prevalence of diabetes found that this condition is highly prevalent in other countries as well (Wild et al., 2004). These alarmingly high and continually growing figures point toward the importance and immediacy of diabetes as a major health issue.

2.4.1 Self-Management of Diabetes

Diabetes can lead to serious complications if not properly treated. These complications may include heart disease, vision loss, kidney disease, amputations of lower extremities, neuropathy (loss of sensation) or dental disease (Hornichter, 1995). Based on recent statistics reported by the Center for Disease Control and Prevention diabetes accounts for considerable proportion of individuals who develop these conditions. Heart disease death rates and the risk of strokes for persons with diabetes is 2 to 4 times higher than for individuals without diabetes (Centers for Disease Control and Prevention, 2008). Data from 2003-2004 indicate, that 3 out of 4 individuals with diabetes have high blood pressure, 130/80 mmHg or more (Centers for Disease Control and Prevention, 2008). In adults (20-74 years old) diabetes is the leading cause for developing blindness and kidney failure (Centers for Disease Control and Prevention, 2008).

Living with diabetes poses challenges to the individual on a day-by-day basis. The management of type 1 diabetes requires regular intake of insulin through injection or a pump. A control of type 2 diabetes can be accomplished by a strict meal plan and exercise.

In case of excess weight, losing some of it is part of treatment goals. Medication is also essential in the treatment of diabetes. Recent data indicates that 14% of adults with diabetes take insulin only, 13% take both insulin and oral medication, 57% are using oral medication only, and 16% do not take either insulin or oral medication (Centers for Disease Control and Prevention, 2008). The quality of life of a person with diabetes can be significantly improved with careful management of the condition. Self-management can improve, stabilize health status and lower the risk of complications (Centers for Disease Control and Prevention, 2008).

Prior studies found that low literacy is prevalent in individuals with diabetes (Powell, Hill, & Clancy, 2007; Williams et al., 1998). One study investigating literacy level in relation to health management and health knowledge in people with diabetes found that literacy was not associated with readiness to take diabetes health actions, but literacy was associated with knowledge of chronic disease, so that individuals with low literacy had less knowledge of diabetes (Powell et al., 2007). These researchers concluded that individuals with low literacy are also willing to participate in self management of their chronic condition.

Individuals who live with diabetes are required to be actively involved in management of their condition to maintain or improve their functioning. Control of the condition enables individuals to fully participate in several areas of life, including work and social life. It is important to acquire a foundational knowledge of the disability to be able to understand risk behaviors that may worsen the condition and healthy behaviors that could stabilize or possibly improve their health. A basic understanding of the condition and behavioral modifications can impact self-efficacy of the person.

Understanding the relationship of health literacy, knowledge of diabetes and health lit-

eracy and their impact on quality of life outcomes is fundamental for disease management. The ability to acquire and effectively use healthcare information, and to have a basic understanding of one's chronic condition is important for the person be able to initiate and sustain healthy lifestyle-modifying behaviors. Involving clients in goal-setting and training in diabetes self-management can help patients to establish and obtain specific behavioral goals (DeWalt et al., 2009). It is important to provide educational materials that are adequate to the person's literacy level to optimize learning and health management benefits for individuals (Powell et al., 2007; Wallace et al., 2009). This knowledge and self-efficacy will empower people with diabetes and will likely motivate them to become active participants and decision makers in their own health management process.

Chapter 3

Method

The current study examined the nature of health literacy in persons with diabetes and explored relationships between health literacy and quality-of-life. Using Livneh's (2001) model of psychosocial adaptation, this study tested associations between health literacy and employment, physical health and psychosocial well-being. This study also examined the influence of disability knowledge and self-efficacy on the direct relationships between health literacy and the four distinct quality of life dimensions studied. While the primary focus was to study predictors of employment, psychological and physical health and social relationships were also investigated in relation to the three main independent variables, health literacy, knowledge of diabetes and diabetes management self-efficacy.

3.1 Research Question and Hypotheses

This study sought to answer the following research questions:

1. How prevalent is low health literacy in individuals with diabetes?

2. Are health literacy skills related to employment outcomes?
3. Are literacy skills related to disparities in health outcomes according to race/ethnicity, SES, or age?
4. How does knowledge of chronic condition and self-efficacy influences specific domains of quality of life (i.e., physical health, employment outcome, emotional and psychological well-being and social functioning)?
5. What is the influence of knowledge of chronic conditions and self-efficacy on the relationship between health literacy and specific domains of quality of life (i.e., physical health, employment outcome, emotional and psychological well-being and social functioning)?

The specific research hypotheses examined were as follows:

Hypothesis 1: Direct effects

1. Health literacy has a direct positive effect on employment outcome.
2. Health literacy has a direct positive effect on social well-being.
3. Health literacy has a direct positive effect on psychological well-being.
4. Health literacy has a direct positive effect on physical well-being.

Hypothesis 2: Testing for knowledge of chronic condition as a mediator

1. Knowledge of chronic condition partially mediates the direct effect of health literacy on employment outcome.

2. Knowledge of chronic condition partially mediates the direct effect of health literacy on social well-being.
3. Knowledge of chronic condition partially mediates the direct effect of health literacy on psychological well-being.
4. Knowledge of chronic condition partially mediates the direct effect of health literacy on physical well-being.

Hypothesis 3: Testing for self-efficacy as a mediator

1. Self-efficacy partially mediates the direct effect of health literacy on employment outcome.
2. Self-efficacy partially mediates the direct effect of health literacy on social well-being.
3. Self-efficacy partially mediates the direct effect of health literacy on psychological well-being.
4. Self-efficacy partially mediates the direct effect of health literacy on physical well-being.

Hypothesis 4: Combined effects of knowledge of chronic condition and self-efficacy on the relationship of health literacy and quality of life outcomes

1. The combined mediation of self-efficacy and knowledge of chronic condition is stronger than their individual effects on the relationship between health literacy on employment outcome.
2. The combined mediation of self-efficacy and knowledge of chronic condition is stronger than their individual effects on the relationship between health literacy on social well-being.

3. The combined mediation of self-efficacy and knowledge of chronic condition is stronger than their individual effects on the relationship between health literacy on psychological well-being.
4. The combined mediation of self-efficacy and knowledge of chronic condition is stronger than their individual effects on the relationship between health literacy on physical well-being.

3.2 Participants and Procedure

The population of interest in this study was persons with diabetes. One hundred and twenty-six individuals participated in this study. Participants were recruited from Michigan. Three different data collection methods had been used: in-person individual and group interviews, mail survey and online survey. The interviews lasted for 30 minutes on average. The majority of participants were recruited from diabetes education and support groups of two major hospitals located in Lansing and Ann Arbor (i.e., the Diabetes Management Program at Ingham Regional Medical Center in Lansing, and the Center for Diabetes at the Saint Joseph Mercy Hospital in Ann Arbor) and from current and former customers of Michigan Rehabilitation Services (MRS). MRS is the public vocational rehabilitation agency in the State of Michigan that provides vocational rehabilitation services to individuals with different types of disabilities, including diabetes. To recruit participants, I first contacted professionals (medical doctors, rehabilitation counselors, and community support group leaders) that work in the direct service of persons with diabetes to ask for permission to advertise the study in their institution. The study was approved by both hospitals' Institutional Review Board (IRB) and by the Michigan State University's IRB. The leadership of MRS also issued a formal

letter in which permission was granted to collect data through their agency.

To recruit individuals from education and support groups, I visited these classes and introduced the study to class attendees. Individuals who manifested an interest to participate were first presented the informed consent (see Appendix A and B). Individuals who gave consent, were directed to complete the survey. Participants were also given the option to set up times at their convenience to complete the tests or to take a test packet home, and later return it in the stamped self-addressed envelope provided to them. The consent was created in compliance with the requirements and guidelines for research on human subjects requested by the Michigan State University's IRB. Saint Joseph Mercy Hospital's IRB requested to modify the consent to include their specific guidelines. As a result a slightly different version of the consent form was used with participants from the Saint Joseph Mercy Hospital. Both versions of the consent are enclosed in the appendix.

I used advertisements and the AWARE database to identify and recruit participants through MRS. The AWARE database is the major data storage program of all current and former MRS clients. Test packets were sent out in two waves to a random sample of current and former customers with diabetes (25.5 % response rate). The packets consisted of a modified version of the advertisement flyer, the informed consent, the instrument and a stamped self-addressed envelope. The flyer was also posted at the agency, informing participants about the study (purpose of the study and duty of participants, eligibility, benefits of participation, payment, and researcher contact information). The flyer could be found in Appendix C.

Zoomerang online survey software tool was used to reach out to potential participants through the internet. The link was distributed to a sample of patients attending diabetes

educational classes held at the Center for Diabetes at the Saint Joseph Mercy Hospital in Ann Arbor but only twelve participants opted to complete the survey online.

The questionnaire consisted of six parts: TOFHLA - Full version (Parker, Baker, Williams, & Nurss, 1995), Perceived Diabetes Self-Management Scale (Wallston et al., 2007), Diabetes Knowledge Test (Gazmararian et al., 2003), World Health Organization Quality of Life Brief version or WHOQOL-BREF (World Health Organization, 1998), Employment and Demographic questions (see Appendix D). There was a preestablished order in the administration of the assessment instruments. The first instrument administered was the health literacy test, starting with the Numeracy section. Next the WHOQOL-BREF measure and the employment items were administered. The self-efficacy and diabetes knowledge measures followed next. Lastly, background and demographic questions aimed at collecting information about the participants' educational background, health insurance information and disability information.

All interview and mail survey respondents received 10 dollars for participation. A raffle was used with the online survey format, and of the 12 online respondents 2 individuals received payment.

Table 3.1 provides a description of the sample in terms of gender, race/ethnicity, education, and employment status.

As far as race-ethnicity the majority self-identified as European American (61.1%) and another large proportion as African American (27.0%). A smaller group of 7.8% indicated that they belong to another racial/ethnic group (Hispanic/Latino, Native American or Multiracial). The average age of participants was 54.66 years (SD= 11.41, Min.=21 , Max.=82). More females than males participated (70 versus 54). In terms of education, almost all par-

Table 3.1: Sample Characteristics

	N	Percent
Gender		
Female	70	55.6
Male	54	42.9
Race/Ethnicity		
White	77	61.1
Black	34	27.0
Other	10	7.9
Education		
High School/GED or Less	48	38.1
Some College No Degree	40	31.7
College Degree or More	37	29.4
Working Now		
Yes	56	44.4
No	67	53.2

Ns vary due to missing data.

ticipants completed at least high school. There was a small number of 5 individuals who did not complete high school, so the "Some high school, no degree" and "High School or High School Equivalency (General Educational Development or GED)" were collapsed into a single category. Of this sample, 38.1% had a high school degree or its equivalent, another 31.7% had some college education, while another 29.4% had a college degree or more education. Less than half, or 44.4% were employed, and slightly more than half of the sample reported not working at the time of the data collection (53.2%).

Specific exclusion criteria was applied to exclude any confounding effects due to certain

individual characteristics. As it has been a standard procedure in other research studies (Arozullah et al., 2006), individuals younger than 18, or persons with severe visual problems, blindness, deafness, dementia or other cognitive impairments were excluded from participation.

I performed power analysis using G*Power 3 (Faul, Erdfelder, Lang, & Buchner, 2007) to determine the required sample size. The family of tests to be used are F-tests, and multiple regression tests in particular. The results of this a priori or prospective power analysis indicated that N=150 is needed to have an 80% of correctly rejecting the null hypothesis with a moderate effect size (input parameters: power = 0.80, the population effect size to be detected was set to a medium effect or $d=0.15$, the prespecified significance level or alpha was established at .05). Due to timelines and budgetary constrains, and the low response rate in participation, data collection was concluded with N=126 responses.

3.3 Variables and Instruments

Independent Variables

Assessment of Health Literacy

Health literacy is the independent variable of main interest for the current study. Functional health literacy is defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

Health literacy was measured using the Test of Functional Health literacy in Adults, or TOFHLA (Parker et al., 1995). While the short form can be completed in slightly more than

10 minutes, the authors of the test recommend using the long form for research purposes. Items of the TOFHLA simulate real life situations a person may encounter in the health care environment. The instrument uses material from health care settings. The reading section measures the person's ability to read and understand information related to health and health care. The numeracy component measures the individual's ability to understand and utilize basic mathematical knowledge needed to function in the health care environment (e.g., interpret prescription labels, or determine if blood glucose is normal based on a chart provided). The two sections combined consist of 67 items (50 reading comprehension items and 17 numeracy items). The test is based on modified Cloze method, where sections are left blank and the person is asked to select from multiple choices (4 answer choices for each missing word) the answer he finds to best complement the sentence. It is a knowledge test of health and utilization of health information.

This test yields a continuous measure, which in several studies was used as a categorical variable. This transformation is accomplished by grouping individuals into inadequate, marginal and adequate skill level at pre-specified cut-points of the continuous scale. Final scores on the reading section are computed by summing the raw points accumulated and they may range from 0 to 50. Scores on the numeracy section are weighted, by multiplying raw points with a constant of 2.941, and this yields final scores ranging between 0 and 50. The combined final scores results from the sum of the scores on the two subtests, and range between 0-100. Cut scores are at 60, and 75 (Nurss, Parker, Williams, & Baker, 2001; Parker et al., 1995). Scores between 0-59 represent inadequate health literacy. At this level individuals will often misread the simple materials, such as prescription bottles and appointment slips. Scores between 60-74 indicate marginal health literacy. It is assumed that the individ-

ual can read and understand simple information, but there are difficulties with processing more complex text. A score between 75-100 denotes adequate literacy. People at this level can properly function in the health care environment, but may encounter some challenges with complex material. TOFHLA subscale and total scores were highly skewed in this sample. To normalize the data, transformations were pursued, but these transformations yielded results that were similar to what was found in the original data. Natural log was used for the reading subscale, and square root for the numeracy and total health literacy scores. As such, the results on the original data are reported in relation to the health literacy variable.

TOFHLA was widely used in previous studies (Baker et al., 1998; Kalichman & Rompa, 2000; Mancuso & Rincon, 2006; Williams et al., 1998). The measure was found to correlate with the Wide Range Achievement Test-Revised (WRAT-R), a widely used instrument to assess basic skills in reading, spelling and arithmetics ($r=.74$). TOFHLA also strongly correlates with the Rapid Estimate of Adult Literacy in Medicine ($r=.84$). Prior studies found that the measure has high internal consistency with a Cronbach alpha of .98 for all items combined (Parker et al., 1995; Nurss et al., 2001). In the present study, the computed Cronbach's alpha was 0.74 for the numeracy subscale, 0.80 for the readings subscale, and 0.85 for all items combined. Numeracy and reading scores were correlated ($r=.65$, $p<0.001$).

When the three categories were created at pre-established cut-scores, I found that only a small percentage (13.5%) of the participating sample has marginal and inadequate level of health literacy skills. Table 3.2 displays results obtained on the current sample.

Dependent Variables

Assessment of Employment Outcome

Several survey items were used to assess employment outcome. Participants were asked to

Table 3.2: Health Literacy in the Participating Sample

	N	Percent
Inadequate	6	4.8
Marginal	11	8.7
Adequate	103	81.7
Missing	6	4.8

Ns vary due to missing data.

report on their past and current employment status. They were asked to report if they ever worked on a paid position, or whether they are currently working. Furthermore, the type of work was also reported (part-time or full-time), and participants were also asked to provide their job title. Data on satisfaction with current employment, information on the average number of hours worked in a week, and hourly wages were also collected. Participants were asked to report if they have any benefits through employment, such as health insurance. They were also asked if they are currently on welfare. These items yielded a comprehensive picture of participants' current employment situation. All these items were based exclusively on self-reports.

Assessment of Physical, Social and Psychological domains of QOL

The World Health Organization Quality of Life-BREF (WHOQOL-BREF) was used to assess the quality-of-life domains of interest to this study (World Health Organization, 1998). This test has a total of 26 items that measures four dimensions of quality of life, physical health, psychological well-being, social relationships and environmental domain. WHOQOL-BREF is the short form of WHOQOL-100, a 100 item quality of life instrument developed by the World Health Organization. The short version was developed to have a brief, convenient,

more concise yet accurate instrument to assess these specific constructs.

Physical Health includes facets such as pain and discomfort, energy and fatigue, sleep and rest. These items inquire about the control the person has over pain, the ease with which relief from pain can be achieved, and about the presence and nature of unpleasant physical sensations. Control over these feelings has a favorable impact on quality of life. Physical health items also ask about energy level, enthusiasm and endurance, the ability to sleep and rest so that the person is able to perform daily activities and social functions. "To what extent do you feel that physical pain prevents you from doing what you need to do?" is a sample item and answer choices include *Not at all*, *A little*, *A moderate amount*, *Very much* and *An extreme amount*.

Items in the **Psychological domain** ask about positive feelings, self-esteem, thinking, memory, concentration and decision making ability, body image and appearance. The more a person is able to experience positive feelings, the better his/her self-esteem and body image is. These positive feelings have a beneficial effect on quality of life outcomes. "How much do you enjoy life?" is a sample item, and answers include, *Not at all*, *A little*, *A moderate amount*, *Very much* and *An extreme amount*.

The **Social Relationships** domain questions pertain to personal relationships, sexual activity, and the amount and quality of social support received by the person. If the person has fulfilling relationships, his/her life quality will likely be better. "How satisfied are you with your personal relationships?" is one sample item, the answer to which include the following categories, *Very dissatisfied*, *Dissatisfied*, *Neither satisfied nor dissatisfied*, *Satisfied* and *Very satisfied*.

The **Environment domain** consists of items pertinent to physical safety and security,

home environment, transportation, financial resources, health and social care, opportunities to acquire new information and skills, participate in recreation and leisure, and the ability to avoid pollution and noise. A favorable combination of these conditions is associated with better quality of life. For most of the questions there is a 5-point Likert scale. A sample question reads as "How satisfied are you with your access to health services?" and the answer choices to this question are *Very dissatisfied*, *Dissatisfied*, *Neither satisfied nor dissatisfied*, *Satisfied* and *Very satisfied*.

Domain scores for the WHOQOL-BREF are calculated by taking the mean of all items included in each domain and multiplying by a factor of four. These scores are then transformed to a 0-100 scale. At the development of the short instrument, four domain confirmatory factor analysis model was employed to assess its dimensionality and factor structure. The four domain structure was confirmed, presenting the four facets of the test as described above (physical health, psychological well-being, social relationships and environmental functioning). Cronbach alpha values for the individual domains were calculated to be .82 for Physical Health, .75 for Psychological Well-being, .66 for Social Relationships, and .80 for the Environment scale (World Health Organization, 1998). These numbers support that the scales have good internal consistency (World Health Organization, 1998).

For the purpose of the current study only the first three domains were studied, Physical health, Psychological Well-being, and Social Relationships. The measure possessed adequate internal consistencies for all three subscales. Cronbach alpha values were .89 for Physical Health, .87 for Psychological Well-being, and .80 for Social Relationships in the participating sample of this study.

Assessment of Self-Efficacy

Self-efficacy is the individual's confidence in own skills and abilities to undertake specific behaviors to obtain a desired outcome (Bandura, 1977). Management of different types of disabilities require different behaviors. Researchers have developed instruments to assess self-efficacy in relation to the unique features of several disabilities. Self-efficacy in the health context pertains to the individual's belief in own abilities to execute recommended behaviors that will lead to desired health outcomes. Such behaviors include medication adherence, compliance with treatment regimens, diet, exercise, and preventive health care.

The *Perceived Diabetes Self-Management Scale (PDSMS)* was used to measure self-efficacy in relation to managing diabetes (Wallston et al., 2007). Research indicates that there is high degree of variability in the extent to which persons perceive themselves efficacious in managing their own health when living with diabetes (Wallston et al., 2007). The test is unidimensional and was created to assess self-efficacy in persons with diabetes. The PDSMS consists of 8 items. Response options for the PDSMS items range from 1 = Strongly Disagree to 5 = Strongly Agree. The total score range from 8 to 40 with higher scores indicating higher levels of self-efficacy in managing diabetes. "It is difficult for me to find effective solutions for problems that occur with managing my diabetes" is a sample item and the person is asked to respond on the 5-point scale. The measure was not found to be correlated with age, time since onset of disability, or education which makes it usable with different age groups or individuals of various socio-economic backgrounds. This measure was positively correlated with self-reported self-care activities, and negatively correlated with glycemic control. These correlations support the validity of the measure. The

internal consistency of this instrument (Wallston et al., 2007) was found to be good, with a Cronbach's alpha of .83.

In the current sample the mean score on the scale was 27.36 (SD=6.29, Min.=12, Max.=40). As far as internal consistency, Cronbach alpha was computed to be .87, indicating acceptable internal consistency of the items of the scale. There were no significant mean-level differences among individuals of different racial/ethnic backgrounds, or between males and females. However, individuals with less education (High school or less) scored significantly lower than the other two groups (i.e., "Some College No Degree" and "College Degree or More"), $F(2,121)=10.66, p<.001$.

Assessment of Knowledge of Chronic Condition

Knowledge of chronic condition is another construct that is unique to different CIDs. The chronic disease knowledge questions were drawn on a study (Gazmararian et al., 2003) that used knowledge questions from earlier developed disease knowledge scales for diabetes, hypertension, asthma, and congestive hearth failure. The purpose of these scales is to capture the mastery of essential concepts that are typically communicated to patients with these disabilities. The instrument for diabetes consists of 11 questions that ask individuals about their knowledge of normal blood glucose levels, symptoms, and complications. Educational material used by the American Diabetes Association (Gazmararian et al., 2003) was used to develop questions for the diabetes scale. Response choices to items are true or false. Scores are computed by the number of correctly answered items. Mean score in the current sample on this scale was 8.85 (SD=1.26, Min.=6, Max.=11). There were no race/ethnicity, gender or education effects noted on outcomes of this scale. The calculated Cronbach's alpha of .28 evidenced poor overall internal consistency for the measure. This figure indicates that the

Diabetes Knowledge test was unreliable for participants of the current research.

Due to issues with the psychometric properties concerning the Diabetes Knowledge test, a subjective self-assessment item was also included in the analysis. This item assesses the individual's general sense of understanding diabetes and its treatment. Individuals were asked to rate their level of understanding of their condition on a 7-point Likert scale, by responding to the question "How would you rate your understanding of diabetes and its treatment?" on the scale ranging between 1=Poor and 7=Excellent (M=5.13, SD=1.43, Min=1, Max=7). Significant race/ethnicity and education effects were noted on this scale. A comparison between European Americans and Individuals with Other Racial/Ethnic backgrounds found a statistical significant difference in the two groups on these ratings $t(70)=2.11$, $p<.05$. European Americans scored higher (M=5.40, SD=1.24) than individuals of other racial-ethnic backgrounds (M=4.80, SD=1.66). In terms of education effects, post hoc comparisons with Bonferroni multiple comparison test indicate that the mean score of individuals with "High School degree or less" is significantly lower than the average for the individuals with "College degree or more" education (M=4.79, SD=1.41 versus M=5.51, SD=1.24).

Control Variables

Background and demographic information were collected as well. Participants were asked to provide information regarding their age, gender, race/ethnicity and educational attainments. Most of this information regarding demographics was discussed at the section describing the sample.

In addition, two more measures were introduced as potentially impacting the four distinct quality of life outcomes of persons with diabetes. Subjectively rated level of interference of diabetes with activities of daily living was one to be controlled, as a potential influencing

factor on employment, physical and psychological well-being, as well as social functioning. Participants were asked to respond to the question "How often does your diabetes prevent you from doing your normal daily activities (ex. work)?" by giving ratings on a 7-point scale, from 1=Never to 7=Frequently ((M=2.44, SD=1.64, Min=1, Max=7). An examination of race/ethnicity effects indicate that European Americans reported less interference of diabetes with activities of daily living than participants from other racial groups, $t(80)=-2.09$, $p=.04$. No gender or education effects were noted on this measure. In terms of employment, individuals who worked at the time of data collection reported significantly less interference of diabetes in their daily functioning than non-working individuals $t(117)=3.12$, $p=.002$, $d=0.56$.

Time since diagnosis was also examined. Individuals diagnosed within the past 5 years appeared to be significantly different from individuals diagnosed with diabetes more than 5 years ago. Individuals diagnosed ≤ 5 years ago were more likely to be employed, $\chi^2(1, N = 120) = 2.90$, $p=.09$, 53.8% of individuals diagnosed 5 years or less time ago worked, however of those diagnosed more than 5 years ago only 38.2% worked. Furthermore, individuals diagnosed five or less than 5 years ago reported better physical health (M=61.61, SD=21.29) than individuals diagnosed more than 5 years ago (M=52.72, SD=23.74), $t(120)=-2.14$, $p=.03$ (two-tailed), $d=.39$. Time since diagnosis also appears to be related to participants' perception of their social relationships, with individuals with 5 years of shorter time since diagnosis reporting better social relationships (M=62.74, SD=22.80 versus M=54.23, SD=25.87), $t(119)=1.86$, $p=.06$.

3.4 Data Analysis

During univariate analysis a series of chi-square, Student t-tests and one-way ANOVAs were used to examine the associations between demographic factors and the variables of main interest. T-tests and one-way ANOVAs examined the relationship of continuous variables. Categorical variables were examined using unadjusted chi-square statistics. Effect sizes were also calculated during these analyses. A thorough comparison of scores of males and females, of individuals of different age categories, those who have the disability for longer time, versus those who acquired the disability more recently, and also individuals of different educational attainments were studied on both outcome measures, and on the main predictors as well.

Regression analyses were planned to test the independent effect of health literacy on quality of life outcome measures, after adjusting for covariates, that include, age, gender, race/ethnicity, and education. Logistic regression was used on categorical outcomes, and multiple linear regression on the continuous dependent variables. Binary logistic regression is a suitable method to examine the association of health literacy with the categorical yes-no type employment outcome measure. For a continuous outcome measure such as physical or emotional well-being ordinary least square regressions were employed.

To test for mediator effects, instead of the traditional method to test mediation effect developed by Baron and Kenny (Baron & Kenny, 1986) the bootstrap approach developed by Preacher and Hayes (Preacher & Hayes, 2004) was planned to be used. This method is suitable to examine the independent and joint mediation effect of diabetes management self-efficacy and diabetes knowledge. I hypothesized that diabetes management self-efficacy and diabetes knowledge mediates the relationship between health literacy and specific quality of life outcomes and these statistical methods are appropriate to test these hypotheses.

Chapter 4

Results

This study had several goals. One goal was to investigate the nature of health literacy, in particular the prevalence of low health literacy in individuals with diabetes. Furthermore, this study also sought to explore whether health literacy skills are related to disparities in health outcomes in individuals of different race/ethnicity, SES, or age. Drawing on Livneh's model of psychosocial adaptation to CID the current study examined the relationship of health literacy, diabetes knowledge and perceived diabetes management self-efficacy with four distinct quality of life outcomes, physical health, psychological well-being, employment and social relationships. It was hypothesized that these three independent measures have a significant direct association with the quality of life outcome measures. Furthermore, it was hypothesized that health literacy affect these outcomes indirectly, through diabetes knowledge and diabetes management self-efficacy. Particularly, the hypothesis stated that diabetes knowledge and diabetes management self-efficacy mediate the relationship of health literacy and quality of life (i.e., physical health, psychological well-being, social relationships, and employment).

Table 4.1: Wages and Hours Worked

	N	Min	Max	Median	Mean	SD
Hours worked in a week on last job	114	6.00	75.00	36.25	34.72	13.63
Weekly earnings on last job	101	43.74	4,500.00	392.50	579.59	649.70
Hours worked in a week on current job	59	5.00	65.00	28.33	29.91	15.38
Weekly earnings on current job	52	45.00	4,500.00	366.39	567.65	737.13

Univariate data analyses were performed to describe the variables of interest in this particular group, and to examine the interrelationship of main independent and dependent measures. Logistic and multiple linear regression were employed to examine the significance of main predictors in relation to the four different quality-of-life measures examined in the study. SPSS.19 for Windows was used for all data analysis.

4.1 Univariate Findings According to Outcome Measures

4.1.1 Employment

Almost all individuals (n=120 or 95.2%) reported that they held paid employment in the past. Less than half of the participating sample (56 or 44.4%) said that they are currently employed either part-time or full-time in a paid position. Of the 56 individuals employed, about half (n=26) said they were employed full-time, and another 30 said that they have part-time employment. Wages and hours worked are summarized in Table 4.1.

Hours worked in a week varied from 6 to 75, with a mean of 34.72 (SD=13.63) and a median of 36.26 for the last job held. As far as current employment, weekly work hours varied

between 5 and 65 hours, with an average of 29.91 (SD=15.38) and a median of 28.33 hours a week. There was significant variation in terms of earnings as well. Weekly earnings varied between \$43.74 and \$4,500.00 as far as last employment, and from \$45.00 and \$4,500.00 for the current job, with means of \$579.59 (SD=649.70) and median of \$392.50 respectively \$567.65 (SD=737.13), Med=366.39.

Of the individuals employed at the time of data collection (n=56) only 26 or 46.4% said that they have benefits on the job (such as health insurance) and 36 individuals said that they were satisfied or very satisfied with their employment. When prompted to report on their outlook on finding employment in the future, 40.4% of all participants said that they are either very or fairly confident that they can find employment in the future.

Univariate statistical analysis found that employed and not employed participants differ significantly in several aspects. An examination of demographic characteristics indicated that gender and employment status were related, $\chi^2(1, N = 121) = 6.46$, $p=.01$, 35% of women worked, while almost 60% of male participants said they did. Race/ethnicity and employment status were also associated, $\chi^2(1, N = 119) = 3.12$, $p=.08$, only 40.3% of European Americans worked, but 57.1% of individuals from other racial/ethnic background worked. Education and employment were associated as well, individuals with more education were more likely to work than individuals who had high school degree, or GED or less than that, $\phi=0.29$, $p=.005$. While only 27.1% of the individuals with "High School Degree, GED or Less" worked in the present, 59.5% of the individuals with "Some College, No Degree" and 54.1% of participants with a "College Degree or More" said they were employed.

In this study time since diagnosis was also examined as having a possible association with employment. There were two groups, and the 5 years elapsed since diagnosis was used as a

Table 4.2: Comparison of Working and Not Working Individuals on the Predictors of Primary Interest

Variables	d	t	df	N	Working		Not Working		
					M	SD	N	M	SD
Age	-.24	1.32	120	55	53.24	9.83	67	55.99	12.60
TOFHLA numeracy	.07	-0.37	120	55	39.51	7.95	67	38.88	10.33
TOFHLA reading	.04	-0.22	118	56	47.02	3.42	64	46.88	3.59
TOFHLA total	.07	-0.37	117	55	86.51	10.32	64	85.70	13.25
Diabetes Knowledge	-.42	2.32	119	55	8.56	1.24	66	9.09	1.25
Understanding Diabetes	.02	-0.10	121	56	5.16	1.51	67	5.13	1.38
Interf. of Diab with ADLs	-.56	3.05	118	55	1.96	1.37	65	2.86	1.78
Self-Efficacy	.38	-2.11	120	56	28.71	6.11	66	26.31	6.39
Physical Health	.77	-4.23	121	56	65.75	23.39	67	49.16	20.08
Psychological Well-Being	.41	-2.28	121	56	66.26	20.07	67	58.03	19.76
Social Relationships	.24	-1.30	119	56	60.79	27.00	65	54.81	23.52

Ns vary due to missing data.

cut-point. Individuals were grouped into the 5 years or less, and more than 5 years groups based on the length of time that elapsed since they were told that they have diabetes. This variable was also associated with employment outcome. Individuals diagnosed 5 or less than 5 years ago were more likely to be employed than individuals diagnosed more than 5 years ago, $\chi^2(1, N = 120) = 2.90, p=.09$, 53.8% of individuals diagnosed 5 years or less time ago worked, however of those diagnosed more than 5 years ago only 38.2% worked.

Table 4.2 compares averages for individuals employed and not employed on the main continuous variables of interest. While individuals not employed were slightly older on average than individuals who were working, a t-test comparing the mean age of individuals

employed and not employed found no difference between the two groups. When comparing health literacy scores of employed and not employed individuals I found that mean scores of the working group was slightly higher than the average of non-employed group, but these differences were not statistically significant. Health literacy was found not to be related to employment at univariate level.

Statistically significant differences were noted at univariate level between the two groups on diabetes knowledge, diabetes management self-efficacy and self-assessed interference of diabetes with activities of daily living. Individuals not working scored higher ($M=9.09$, $SD=1.25$) on the Diabetes Knowledge test than individuals who are working ($M=8.56$, $SD=1.24$), $t(119)=2.32$, $p=.02$ (two-tailed), $d=-.42$. Individuals not working reported higher level of interference of diabetes with activities of daily living ($M=2.86$, $SD=1.78$) than individuals who were working ($M=1.96$, $SD=1.37$), $t(118)=3.05$, $p=.003$ (two tailed), $d=-.56$. Individuals who were working had higher level of diabetes management self-efficacy ($M=28.71$, $SD=6.11$) than individuals who were not working ($M=26.31$, $SD=6.39$), $t=-2.11$, $p=.04$ (two-tailed), $d=.38$.

Individuals with diabetes who were working reported better physical health, $t(121)=-4.23$, $p<.001$, $d=.77$, and better psychological functioning $t(121)=-2.28$, $p=.02$, $d=.41$, but there was no statistically significant difference in their subjective sense of the quality of their social relationships, $t(119)=-1.30$, $p=.24$, $d=.24$.

4.1.2 Physical Health

Physical health was another quality of life dimension of primary interest for the study. Using a series of t-tests, ANOVA, and correlations, the univariate associations between physical

health and other important predictor and control variables were tested.

One-way ANOVA showed a significant association between race/ethnicity and physical health, $F(2,120)=3.71$, $p=.03$. Post-hoc tests (Tamhane) revealed a statistically significant difference between White and African American individuals, with European Americans reporting better physical health ($M=59.52$, $SD=21.62$) than individuals of African American racial/ethnic background ($M=47.79$, $SD=22.84$). There was no statistically significant difference between males and females on this measure. However the physical health of individuals of different levels of education was significantly different. Individuals with more education reported better physical health. Individuals with college or more education scored highest ($M=63.84$, $SD=23.28$), followed by those with some college education ($M=56.96$, $SD=23.39$) and individuals with high school or GED, or even less than high school education reported having the worst physical health ($M=49.63$, $SD=21.02$). In terms of time since diagnosis and physical health there was a statistically significant univariate association. Individuals diagnosed five or less than 5 years ago reported better physical health ($M=61.61$, $SD=21.29$) than individuals diagnosed more than 5 years ago ($M=52.72$, $SD=23.74$), $t(120)=-2.14$, $p=.03$ (two-tailed), $d=.39$.

Bivariate correlations (Table 4.3) showed a strong positive association between diabetes management self-efficacy and physical health ($r=.61$, $p<.001$), and level of understanding of diabetes and its treatment with physical health ($r=.36$, $p<.001$). There was a significant negative correlation between interference of diabetes with activities of daily living and physical health ($r=-.57$, $p<.001$). Knowledge of diabetes and health literacy were not associated with self-rated physical health.

Table 4.3: Pearson Correlation Coefficients for Main Independent Measures and Physical Health Outcome Measure

Variables	1	2	3	4	5	6
Physical Health	-					
Interf. of Diab with ADLs	-.57**	-				
Understanding Diabetes	.36**	-.21	-			
Diabetes Knowledge	-.07	.14	.30	-		
Diabetes Management Self-Efficacy	.61**	-.48	.43	-.04	-	
TOFHLA total	.13	-.29	.20	-.04	.13	-

** $p < .01$, * $p < .05$. Ns vary from 117 to 125.

4.1.3 Psychological Well-being

A univariate statistical analysis for gender, race, education effects on psychological health found no significant relationships between these demographic characteristics and the subjective evaluation of psychological well-being. While the mean psychological well-being scores of males ($M=63.85$, $SD=20.69$) was somewhat higher than the average for females ($M=60.51$, $SD=19.31$) these differences were not statistically significant. In terms of race/ethnicity, European Americans ($M=62.80$, $SD=20.62$) had higher mean scores than African Americans ($M=59.31$, $SD=18.35$), while the Other races category ($M=64.25$, $SD=21.76$) scored higher than both African Americans and European Americans, but none of these differences were statistically significant. Participants with higher levels of education had higher mean scores on psychological well being. Individuals with "College degree or more" rated their psychological health highest ($M=65.16$, $SD=22.83$), followed by individuals with "Some college, no degree" ($M=64.53$, $SD=18.75$), while mean scores of participants with "High School Degree, or GED or less education" were the lowest ($M=56.61$, $SD=18.21$), but these effects were not

Table 4.4: Pearson Correlation Coefficients for Main Independent Measures and Psychological Well-being Outcome Measure

Variables	1	2	3	4	5	6
Psychological Well-being	-					
Interf. of Diab with ADLs	-.53**	-				
Understanding Diabetes	.37**	-.21	-			
Diabetes Knowledge	-.05	.14	.30	-		
Diabetes Management Self-Efficacy	.65**	-.48	.43	-.04	-	
TOFHLA total	.04	-.29	.20	-.04	.13	-

** $p < .01$, * $p < .05$. Ns vary from 121 to 125.

statistically significant, $F(2,121)=2.53$, $p=.08$. Time since diagnosis, or whether the person was diagnosed within the past 5 years, or more than 5 years ago is not associated with psychological well-being $t(120)=-1.42$, $p=.16$.

Bivariate correlations capturing the association of psychological well-being with the continuous measures of major importance are presented in Table 4.4. Diabetes management self-efficacy and psychological well-being are positively correlated ($r=.65$, $p<.001$), similarly to level of understanding of diabetes and its treatment with psychological well-being ($r=.37$, $p<.001$). Subjectively rated level of interference of diabetes with activities of daily living is negatively related to psychological well-being.

4.1.4 Social Relationships

Univariate analysis of differences in self-assessed social relationships according to demographic variables found no significant differences in relation to race/ethnicity, gender or education level. Average scores of social relationships were highest for individuals of Other

Table 4.5: Pearson Correlation Coefficients for Main Independent Measures and Social Relationship Outcome Measure

Variables	1	2	3	4	5	6
Social Relationships	-					
Interf. of Diab with ADLs	-.43**	-				
Understanding Diabetes	.44**	-.21	-			
Diabetes Knowledge	.13	.14	.30	-		
Diabetes Management Self-Efficacy	.47**	-.48	.43	-.04	-	
TOFHLA total	-.02	-.29	.20	-.04	.13	-

** $p < .01$, * $p < .05$. Ns vary from 119 to 125.

racial ethnic background (M=66.67, SD=27.32), followed by White Americans (M=59.27, SD=24.23), while African Americans (M=52.21, SD=25.65) scored lower in this measure, but the differences were not statistically significant, $F(2,118)=1.56$, $p=.21$. Comparisons of average scores for males and females showed very similar findings, (M=57.31, SD=24.57 for males and M=58.49, SD=25.75 for females). Individuals with more education rate their social relationships higher (M=59.23, SD=28.85 for those with "College degree or more", M=58.23, SD=23.58 for those with "Some college, no degree", and M=55.43, SD=23.65 for the individuals with "High school degree, or GED or less education") but these differences were not statistically significant. Similarly to the other outcomes, time elapsed since diagnosis appears to have an impact on the ratings individuals with diabetes assign to the quality of their social relationships. Individuals diagnosed within the last 5 years rate their social relationships more favorably (M=62.74, SD=22.80) than individuals who have been diagnosed more than 5 years ago (M=54.23, SD=25.87), $t(119)=-1.86$, $p=.06$.

Correlations between the independent variables of main interest and social relationships

are presented in Table 4.5. Individuals who experiences high level of interference of diabetes with their activities of daily living, reported less satisfaction with their social relationships ($r=-.43$, $p<.01$). Diabetes management self-efficacy was positively associated with social relationships ($r=.47$, $p<.01$), and similarly, the level of understanding of diabetes and its treatment was positively associated with social relationships ($r=.44$, $p<.01$). Diabetes Knowledge and Health Literacy however was not related to satisfaction with one's social relationships.

4.2 Findings in Relation to the Research Questions

There were two primary goals of the current study : 1) To investigate the nature of health literacy in individuals with diabetes; 2) To examine the associations between health literacy, self-efficacy, diabetes knowledge and different quality of life outcomes, and to determine whether the associations between health literacy and quality of life outcomes, if there are such associations, are mediated by diabetes management self-efficacy and diabetes knowledge.

4.2.1 Research Question 1: The Prevalence of Low Health Literacy in Individuals with Diabetes

Research question 1 asked about the prevalence of low health literacy in individuals with diabetes. Health literacy was measured with the Test of Functional Health Literacy in Adults (TOFHLA). Using pre-defined cut scores to group individuals into three different levels of health literacy development, findings suggest that a large proportion of participants have adequate health literacy level. Table 3.2 presents the distribution of the sample at the three different levels of health literacy. A small group of six individuals representing 4.8% of the studied sample had inadequate health literacy. Another 11 individuals (8.7%) have marginal

health literacy skills. A large proportion of the participating group (n=103, or 81.7%) had adequate health literacy. This finding suggests that 4 out of 5 individuals have adequate health literacy skills in this group of individuals with diabetes.

4.2.2 Research Question 2: The Relationship of Health Literacy Skills with Employment Outcomes

Research question 2 asked whether health literacy skills are associated with employment outcomes. A dichotomous measure was created to operationalize employment outcome. Successful employment outcome was defined as full or part-time employment that was performed for a monetary compensation. A total of 20 individuals reported being retired. These individuals were removed from the analysis. Data for the remaining 106 individuals were included for the data analysis. An independent sample t-test examined the association of health literacy with employment outcome. The outcome of this analysis indicated that there is no association between employment outcome and health literacy. Individuals who worked performed slightly higher on the health literacy test, but the differences were not statistically significant. As such, no further testing was pursued employing the logistic regression to examine the effect of health literacy on employment in the context of other important predictor and control variables, as it was originally planned.

4.2.3 Research Question 3: The Relationship of Health Literacy Skills with Social Functioning, Psychological Well-being and Physical Health

Research question 3 examined whether health literacy skills are related to social functioning, psychological well-being and physical health. Bivariate correlations were computed to examine the association of health literacy with social functioning, psychological well-being and physical health status. Findings indicate that health literacy was not associated with any of these three quality of life outcomes. Health literacy and physical health are not associated ($r=.14$, ns), neither health literacy and psychological well-being ($r=.04$, ns), nor health literacy and social relationships ($r=-.02$, ns).

4.2.4 Research Question 4: The Relationship of Health Literacy Skills with Disparities in Health Outcomes According to Race/Ethnicity, SES, and Age

Research question 4 asked whether literacy skills are related to disparities in health outcomes according to race/ethnicity, SES, and age. Table 4.6 presents means and standard deviations of health literacy scores separately for the three racial/ethnic groups. One-way ANOVAs support significant race/ethnicity effects on both subscales and on the total health literacy scale. Mean differences on the numeracy, $F(2,118)=3.20$, $p=.04$, as well as reading, $F(2,117)=3.05$, $p=.05$ and on the total scales were statistically significant, $F(2,115)=3.54$, $p=.03$. This evidence supports the hypothesis that health literacy skills are related to discrepancies in health outcomes based on racial/ethnic background.

Table 4.6: Scores on the Health Literacy Scale by Race/Ethnicity

Variables	European American		African American		Other	
	M	SD	M	SD	M	SD
TOFHLA numeracy	40.95	8.11	36.33	11.64	37.40	6.60
TOFHLA reading	47.61	3.16	45.91	3.79	46.89	2.37
TOFHLA total	88.47	10.23	82.03	15.02	84.89	7.37

Table 4.7: Scores on the Health Literacy Scale by Race/Ethnicity (2 groups)

Variables	European American		All Others		Cohen's d
	M	SD	M	SD	
TOFHLA numeracy	40.95	8.11	36.58	10.62	0.48
TOFHLA reading	47.61	3.16	46.12	3.53	0.45
TOFHLA total	88.47	10.23	82.66	13.68	0.50

For the purpose of regression analyses all other racial/ethnic groups were combined (see Table 4.7). A comparison of individuals of European American background with the group of individuals of all other races found that European Americans scored significantly higher than all others combined on the health literacy measures.

An examination of health literacy scores based on SES found no evidence in support of health disparities that were noted in relation to SES. The different SES categories, operationalized as annual household income do not appear to present disparities in health literacy. While the averages in higher SES groups are slightly higher (see Table 4.8), the differences are not significantly different neither for the health literacy subscales nor the total scale.

While other studies suggest that older adults have lower health literacy, the current findings suggest no differences in health literacy scores among individuals from different age groups. Table 4.9 displays scores on the subscales and on the main scale for different age

Table 4.8: Scores on the Health Literacy Scale by SES

Variables	\$20,000 or less		\$20,001 - \$40,000		\$40,001 or more	
	M	SD	M	SD	M	SD
TOFHLA numeracy	38.24	11.58	40.56	7.59	39.57	7.61
TOFHLA reading	46.52	4.01	47.67	2.82	47.66	2.34
TOFHLA total	84.83	15.05	87.96	9.48	87.20	9.06

Table 4.9: Scores on the Health Literacy Scale by Age Categories

Variables	49 or less		50 - 59		60 or more	
	M	SD	M	SD	M	SD
TOFHLA numeracy	40.64	8.99	37.39	10.37	40.18	7.91
TOFHLA reading	46.75	3.55	46.55	4.24	47.56	2.11
TOFHLA total	87.34	11.80	84.07	13.71	87.56	9.44

categories. This evidence indicates comparable levels of health literacy in adults, regardless of age category.

4.2.5 Research Question 5: The Effect of Diabetes Knowledge and Diabetes Management Self-efficacy on the Quality of Life Domains

Research question 5 asked if knowledge of chronic conditions and self-efficacy influence the investigated domains of quality of life (i.e., physical health, employment outcome, psychological well-being and social relationships) in people with diabetes. To answer this question, logistic and ordinary least square regression analyses was employed.

To test the effect of knowledge of diabetes and diabetes management self-efficacy on

employment a logistic regression model was constructed. Variables with a significant univariate relationship with the outcome ($p < .25$) were considered for the full model (Hosmer & Lemeshow, 2000). Both knowledge of diabetes and diabetes management self-efficacy were associated with employment outcome at univariate level (individuals who were employed reported higher level of self-efficacy but were less knowledgeable of diabetes than those who did not work). Furthermore, the level of interference of diabetes with activities of daily living, and time since diagnosis were also included in the model, as they were identified as important variables to be associated with employment at univariate level. I also adjusted to physical and psychological health, and diabetes intrusiveness in ADLs (because there were significant group mean differences with individuals who worked, reporting better physical and psychological health, and saying they experience less intrusion of the condition of diabetes in their activities of daily living).

In sum, several patient characteristics were associated with employment status in univariate analysis. Patients who were male, better educated, diagnosed with diabetes within the past 5 years, had higher levels of diabetes management self-efficacy, higher levels of self-rated physical and psychological health, and reported less interference of diabetes with their daily living activities, were more likely to be employed.

A number of covariates that appeared to affect employment were included in the regression model (Table 4.10). Due to differences between physical and psychological health between employed and not employed individuals, the model accounted for these effects. After adjusting for differences in age, gender, race/ethnicity, self-reported physical and psychological health, self-efficacy, diabetes knowledge, interference of diabetes with ADLs it was found that diabetes management self-efficacy and diabetes knowledge have no direct relationship

Table 4.10: Predicting Employment Outcome Using Logistic Regression

Variables	OR	Sig.	95% CI
Diabetes Management Self-Efficacy	0.92	0.24	0.81-1.05
Diabetes Knowledge	0.82	0.41	0.50-1.33
Physical Health	1.08	0.00	1.04-1.13
Psychological Well-Being	0.95	0.06	0.90-1.00
Interference of diabetes with ADLs	0.60	0.02	0.39-0.93
Time Since Diagnosis	0.54	0.31	0.16-1.79
Age	1.02	0.48	0.96-1.08
Female	0.24	0.02	0.07-0.83
Other Racial/Ethnic Group	6.38	0.01	1.64-24.82
High School or Less	0.38	0.18	0.09-1.59
Some College no Degree	2.89	0.16	0.65-12.79
Constant	35.19	0.24	

Hosmer and Lemeshow Test statistic = 8.06, df=8, p=.43

Nagelkerke R-Square or Pseudo R-square = 0.55

with employment. Physical health and the level of interference of diabetes with ADLs are significant predictors of employment outcome.

While there was an unadjusted effect of self-efficacy and diabetes knowledge on employment, in the adjusted model self-reported physical health and the level of interference of diabetes with ADLs are the main statistically significant independent effects that explain the odds of one being employed. The better the persons health and the least diabetes symptoms interfere with ADLs, the better the odds of one being employed is. Although high levels of self-reported diabetes management self-efficacy is strongly associated with employment, the causal pathways for this relation is likely to be through physical health and through the

Table 4.11: Predicting Physical Health Using Ordinary Least Square Regression

Variables	B	SE B	β	p-value
Diabetes Management Self-Efficacy	1.41	0.33	0.39	0.00
Understanding Diabetes	2.64	1.31	0.16	0.05
Interference of diabetes with ADLs	-4.91	1.08	-0.36	0.00
Time since diagnosis	-1.96	3.29	-0.04	0.55
Age	0.05	0.14	0.02	0.73
Female	-1.73	3.20	-0.04	0.59
Other race	0.05	3.39	0.00	0.99
High School Degree or less	-1.14	3.91	-0.02	0.77
Some college no degree	-7.64	3.79	-0.16	0.05
Constant	19.26	13.99		0.17

Note: $R^2 = .54$ ($R^2 - Adjusted = .50$).

lack of interference of diabetes with ADLs.

To construct the multiple regression model for the **physical health** univariate associations were carefully examined. Positive correlation was found between diabetes management self-efficacy and physical health ($r=.61$, $p<.001$), and level of understanding of diabetes and its treatment with physical health ($r=.36$, $p<.001$) (Table 4.3). A significant negative correlation was identified between interference of diabetes with activities of daily living and physical health ($r=-.57$, $p<.001$). Diabetes knowledge and health literacy were not associated with self-rated physical health, as a result these two variables were not entered into the multivariable model.

When I examined the effect of self-efficacy on physical health, I found a significant univariate relationship (Table 4.11), that holds even after adjusting for basic demographics,

psychological well-being and social relationships. The statistically significant zero-order correlation between diabetes management self-efficacy and physical health ($r = .61, p < .001$) persisted after controlling for the other variables in the model, indicating an independent non-redundant effect of self-efficacy on self-reported physical health.

Self-efficacy has an independent direct effect on health, and possibly has an indirect effect on employment through physical well-being. As it has been found, self-efficacy is associated with health. Health and lack of interference of diabetes in daily living activities in turn affects the individual's ability to work.

In order to be able to test the relationship of self-efficacy and diabetes knowledge on **psychological well-being**, an ordinary least square regression model was examined (Table 4.12). Variables that showed a significant association with psychological health at univariate level were selected for the regression model. Bivariate correlations capturing the association of psychological well-being with the continuous measures of major importance presented in Table 4.4 indicate a significant correlation between diabetes management self-efficacy, level of understanding of diabetes and its treatment, and subjectively rated level of interference of diabetes with activities of daily living with psychological well-being.

As a result, these variables were entered into the regression model. An inspection of results of the regression analysis (Table 4.12) reveals that the significant univariate effect of diabetes management self-efficacy remains significant in the multiple regression model as well. Diabetes management self-efficacy has a significant direct effect on psychological well-being in the adjusted model as well. Individuals with higher levels of diabetes management self-efficacy report better psychological well-being. Also, the lack of interference of diabetes with daily living activities influences psychological well-being positively, and this

Table 4.12: Predicting Psychological Well-being Using Ordinary Least Square Regression

Variables	B	SE B	β	p-value
Diabetes Management Self-Efficacy	1.53	0.28	0.48	0.00
Understanding Diabetes	1.85	1.05	0.13	0.08
Interference of diabetes with ADLs	-3.24	0.94	-0.27	0.00
Age	0.15	0.12	0.09	0.22
Female	-1.72	2.78	-0.04	0.54
Other race	2.83	2.88	0.07	0.33
High School Degree or less	1.67	3.39	0.04	0.62
Some college no degree	-1.92	3.31	-0.05	0.56
Constant	10.07	11.80	0.40	

Note: $R^2 = .52$ ($R^2 - Adjusted = .49$).

direct relationship holds in the multiple regression model as well. The level of understanding of diabetes and its treatment as a subjectively reported knowledge component also has a positive association with psychological health, at $p=.08$ statistical significance level.

To examine the relationship of diabetes management self-efficacy and diabetes knowledge on **social relationships**, similarly, I tested an ordinary least square regression model. While the relationship between diabetes knowledge was found not to be related to the quality of social relationships, the subjectively rated level of understanding of diabetes and its treatment is positively correlated to this quality of life outcome. Consequently, this measure was introduced in the model. Also, perceived diabetes self-management scores were significantly related with individuals' perception of their social relationships. In turn, interference of diabetes with activities of daily living has a significant negative correlation with the outcome, supporting that individuals who's condition interferes with their daily functioning rate their

Table 4.13: Predicting Social Relationships Using Ordinary Least Square Regression

Variables	B	SE B	β	p-value
Diabetes Management Self-Efficacy	0.91	0.41	0.23	0.03
Understanding Diabetes	5.37	1.66	0.30	0.00
Interference of diabetes with ADLs	-4.02	1.36	-0.27	0.00
Time since diagnosis	-4.12	4.13	-0.08	0.32
Age	0.19	0.18	0.09	0.28
Female	-0.80	4.03	-0.02	0.84
Other Race	4.01	4.27	0.08	0.35
High School Degree or less	7.31	4.90	0.14	0.14
Some college no degree	0.06	4.75	0.00	0.99
Constant	3.27	17.60		0.85

Note: $R^2 = .38$ ($R^2 - Adjusted = .32$).

social relationships lower. Time since diagnosis also appears to be related to participants' perception of their social relationships. Individuals diagnosed 5 or less than 5 years ago have better social relationships.

Regression results are displayed in Table 4.13. The significant univariate associations between diabetes management self-efficacy, level of understanding of diabetes and its treatment, and interference of diabetes with activities of daily living and social relationships hold after controlling for demographics and other relevant variables. Individuals who feel efficient in managing their diabetes, rate higher their level of understanding of diabetes and its treatment, and consider that diabetes interfere less with their condition give a better rating to their social relationships.

4.2.6 Research question 6: The effect of Diabetes Knowledge and Diabetes Management Self-efficacy on the Relationship between Health Literacy and the Quality of Life outcomes studied

Research Question 6 asked whether diabetes knowledge and diabetes management self-efficacy influence the relationship between health literacy and the investigated domains of quality of life (i.e., physical health, employment outcome, emotional and psychological well-being and social functioning). The answer to this question was not pursued, due to the lack of significant direct association between health literacy and the four quality of life domains examined.

Chapter 5

Discussion

5.1 Summary of Results

This study had several goals. One goal was to investigate the nature of health literacy, in particular the prevalence of low health literacy in individuals with diabetes. Furthermore, this study also sought to explore whether health literacy skills are related to disparities in health outcomes according to race/ethnicity, SES, or age. The study also examined the relationship of health literacy, diabetes knowledge and perceived diabetes management self-efficacy with four distinct quality of life outcomes, physical health, psychological well-being, employment and social relationships. It was hypothesized that the three independent measures have a significant direct association with the quality of life outcome measures. It was also postulated that health literacy affects these outcomes indirectly, through diabetes knowledge and diabetes management self-efficacy. Particularly, the hypothesis stated that diabetes knowledge and diabetes management self-efficacy mediate the relationship of health literacy and quality of life (i.e., physical health, psychological well-being, social relationships,

and employment).

In relation to the **1st research question** it was found that low health literacy is not prevalent in individuals with diabetes. Of the current sample, only six individuals (4.8%) had inadequate and 11 individuals (8.7%) had marginal health literacy skills. Four in five individuals with diabetes (81.7%) had adequate health literacy skills.

The most important finding, pertains to the **2nd research question**. This question examined the association of health literacy with employment. Information on employment status of participants indicates that half of the participating sample (56 or 44.4%) works either full- or part-time. There was great variation in the number of weekly work hours, and hourly wages. Of the employed group less than half, 46.4% had benefits on the job (such as health insurance) and 64.3% stated that they were satisfied or very satisfied with their employment. As far as future employment 40.5% of all participants felt confident it is possible to obtain a job.

This study hypothesized, that health literacy is a significant determinant of employment outcomes. The current findings refuted this hypothesis. While this data reported a small difference between mean health literacy scores of employed and not employed individuals, with employed individuals performing higher on the health literacy test, these differences were not statistically significant.

The **3rd research question** asked whether health literacy skills are related to social functioning, psychological well-being and physical health in this group of individuals with diabetes. Current findings suggest that there are no associations among health literacy skills with any of these three quality of life outcomes.

The **4th research question** investigated the relationship of health literacy to disparities

in health outcomes based on race/ethnicity, SES and education. Current findings support significant race/ethnicity effects on both subscales and on the total health literacy scale. However, there were no differences in health literacy scores based on SES and age. While the averages in higher SES groups are slightly higher, the differences are not statistically significant neither for the health literacy subscales nor the total scale. While prior research found lower health literacy in older adults, the current findings suggest no differences in health literacy scores among individuals from different age groups. This evidence indicates comparable levels of health literacy in adults, regardless of age category. This parallels education attainments in different age categories. In all three age categories (≤ 49 , 50-59, ≥ 60) the distribution of individuals for the three education levels were comparable (almost 1/3 of each group had "College Degree or more" education).

The **5th research question** examined the associations between diabetes knowledge and diabetes management self-efficacy and the quality of life outcomes studied in present research. In terms of **employment outcomes**, several patient characteristics were associated with successful employment in univariate analysis. Patients who were male, better educated, diagnosed with diabetes within the past 5 years, had higher levels of self-efficacy, higher levels of self-rated physical and psychological health, and reported less interference of diabetes with their daily living activities, were more likely to be employed. In the multivariable model, after adjusting for differences in age, gender, race/ethnicity, self-reported physical and psychological health, self-efficacy, diabetes knowledge, interference of diabetes with ADLs I found that physical health and the level of interference of diabetes with ADLs are significant predictors of employment outcome, but neither diabetes management self-efficacy nor diabetes knowledge are significant in predicting employment.

While there was an unadjusted effect of self-efficacy and diabetes knowledge on employment, in the adjusted model self-reported physical health and the level of interference of diabetes in ADLs are the main statistically significant independent effects that explain the odds of one being employed. The better the persons health and the least diabetes symptoms interfere with ADLs, the better the odds of one being employed is. Although high levels of self-reported diabetes management self-efficacy is strongly associated with employment, the causal pathways for this relation is likely to be through physical well-being and through the lack of interference of diabetes with ADLs.

In relation to **physical health** only the effect of self-efficacy was tested, because knowledge of diabetes and health literacy were not associated with self-rated physical health at univariate level. Level of understanding of diabetes and its treatment positively correlated with physical health ($r=.36$, $p<.001$) while interference of diabetes with ADLs showed a negative correlation with this outcome. The effect of diabetes management self-efficacy holds in the adjusted model as well, supporting the presence of an independent non-redundant effect. Level of understanding of diabetes and its treatment positively affects physical health ($\beta=.16$, $p=.05$).

A joint analysis of the relationship of diabetes management self-efficacy with physical health and employment, suggests that self-efficacy has an independent direct effect on health, and possibly has an indirect effect on employment through physical well-being. Diabetes management self-efficacy is positively associated with health. Health and lack of interference of diabetes in daily living activities in turn affects the individual's ability to work.

Diabetes management self-efficacy, level of understanding of diabetes and its treatment, and subjectively rated level of interference of diabetes with activities of daily living were sig-

nificantly correlated with **psychological well-being** (Table 4.4) at univariate level. These associations hold in the adjusted model as well. Individuals with higher levels of diabetes management self-efficacy and better understanding of diabetes and its treatment ($p=.08$) report better psychological well-being. A person who reports that diabetes does not interfere with ADLs also gives a better rating to his/her psychological well-being.

In relation to the last outcome measure, **social relationships** it was found that the significant univariate associations with diabetes management self-efficacy, level of understanding of diabetes and its treatment, and interference of diabetes with ADLs hold after controlling for demographics and other relevant variables. Individuals who felt efficient in managing their diabetes, rate higher their level of understanding of diabetes and its treatment, and consider that diabetes interfere less with their condition give a better rating to their social relationships. While time since the person was told he/she has diabetes is a significant factor at univariate level (with individuals diagnosed within the past 5 years reporting better social relationships), in the multivariable model this factor is not significant any longer.

As far as the **6th research question** of the study, it could not have been answered, due to findings that answered prior questions. Because of the lack of direct relationship between health literacy with any of the four distinct quality of life domains, the mediation test was no longer necessary.

5.2 Limitations

This research has several limitations that need to be considered when discussing current findings. One drawback of the study is related to sample characteristics. This study involves

a convenience sample, that causes limitations in generalization of results to the entire populations of individuals with diabetes. It is difficult to judge the representability of the current sample and consequently the extent to which these findings could be generalized to the population of persons with diabetes. The study aimed at investigating the population of persons with diabetes, but accomplished to recruit a convenience sample, that is different in certain aspects. A recently published report provides the most current data on the demographic profile of persons with diabetes living in the United States (Centers for Disease Control and Prevention, 2011). This data suggests that there is a difference in the prevalence of diabetes by age, gender and race/ethnicity. Certain age and racial/ethnic groups are at higher risk of developing diabetes. Diabetes occurs in higher rates in males, individuals of older age, and certain racial/ethnic groups. Center for Disease Control and Prevention (2011) reports that the risk of diagnosed diabetes is 18% higher among Asian Americans, 66% higher among Hispanics, and 77% higher among non-Hispanic African Americans than it is in White Americans. The current study however has higher rates of female participants, in spite of evidence indicating higher prevalence of diabetes in males. Reasons that could explain this discrepancy could be that females are more willing to favorably respond to invitations to participate in research studies and also they might be more willing to seek out diabetes education and support groups. Participants were recruited from diabetes educational and support groups, and through regular mail contacts. Participant contact information from the MRS database was selected in a manner to ensure representability of the participating sample (in terms of race/ethnicity, education and age). In spite of these efforts, the sample was particularly skewed in terms of participant educational attainment. As a result, there are severe limitations in terms of generalizing of current findings beyond the current sample. It is possible

that through support groups as well was easier to motivate better educated individuals to complete the instruments. Instead of generalizing current findings to the entire population of persons with diabetes living in the United States, current findings could be used to draw conclusion on a subset of this population, specifically persons with diabetes who have higher levels of education overall. Convenience sampling resulted in an oversampling of females and better educated individuals. As such, it becomes of critical importance to consider these characteristics when thinking about these results in relation to the population.

The size of the sample also warrants replication before generalizing these findings. While data collection spanned over eight months, it was a significant challenge to obtain the desired number of participants, in spite of the fact that participation was monetarily compensated. TOFHLA takes approximately 22 minutes to complete, and the rest of the packet can also take another 10-15 minutes, which could explain why some individuals refused to participate and stay in class for an additional 30-35 minutes. Due to these challenges in recruiting participants for the study the sample size was slightly lower than what was suggested by the a priori power analysis. As a result, regression analysis were conducted with the available sample. The stability of current results might not be optimal, as a result these findings must be treated with caution and the study replicated with larger samples. More compensation or other recruitment methods should be employed to better motivate individuals to participate.

Prior studies noted that the relation of health literacy to health outcomes and use of healthcare is different in various patient populations and in different healthcare systems (Baker et al., 1998). This study controls for patient population by narrowing its focus on diabetes only, but the generalizations of findings will likely be limited to individuals with diabetes who live only in the United States, highly likely due to differences in the way the

healthcare system is structured and accessed in other countries.

Another limitation stems from the fact that many individuals attended diabetes education classes in the past or at the time of data collection (85.7%). The other small proportion (14.3%) never had exposure to diabetes education materials. As a result, this content could have impacted results on the diabetes knowledge test to some extent.

As already stated, health literacy measured within this study aimed at operationalizing functional literacy, specifically reading and computational ability. These skills are intraindividual characteristics, yet several studies already noted that the construct of health literacy is broader and transcends individual capacity. Some studies provide a more comprehensive view and conceptualization of this construct, that incorporates culture, and the medical system with which the person comes into contact (Adkins & Corus, 2009). Due to the complexity of this definition, there are no psychometrically sound measures currently available to measure all these aspects. Due to limitations in the measures, in this research functional health literacy was operationalized that is conceptualized as a characteristic within the individual. Other studies, with more comprehensive measurement instruments would possibly bring more accurate results.

5.3 Findings in the Light of Theory

Livneh's (2001) quality of life based model illustrating psychosocial adaptation to CID presented in Figure 1.1 was partially supported by the data. This model was adopted to the purpose of this study so that adaptation to ongoing challenges that individuals with disabilities encounter in their daily living was examined, rather than adaptation to the recently acquired disability or chronic illness. In the modified model I conceptualized the ongoing

adaptation process in response to changes and altered health when someone is living with a chronic illness and disability. I postulated that process variables influence significantly several quality of life outcomes. The measurement model specifically discussed the variables examined in this study, and the hypothesized relationships among them.

The model was partially supported by several findings from this research. This study created empirical evidence to support the significance of diabetes management self-efficacy, level of understanding of diabetes and its treatment, and the lack of interference of diabetes symptoms on ADLs in predicting distinct quality of life domains in this sample of individuals with diabetes.

No significant relationship was detected between health literacy with any of the four distinct quality of life domains. It is possible that there is no relationship between these constructs. In contrast, if these constructs are associated, but this study could not detect this association, there could be several reasons for it. One such reason could be that the relationship might be different from what was tested in this research. Other reasons for not being able to detect such relationships could be due to issues that occurred due to characteristics of the sample or the measurement instruments. In this study there was a restriction on range of the health literacy measure. As it was described in detail, this measure was very skewed, and most individuals performed really well on the instrument. Many individuals who participated had education beyond high-school and was really challenging to enroll individuals from lower education levels to participate, and these limitations yielded a very skewed data, consequently influencing the results when examining the effects of health literacy on the different quality of life domains.

The current data supports the hypothesized relationships among several predictor and

outcome variables. Individuals' sense of self-efficacy in regard to the management of their condition has a significant direct effect at both univariate level, and in the adjusted multiple regression model as well on physical health, psychological well-being and social relationships. Self-efficacy was associated with employment as well at univariate level. Self-efficacy is a process variable in Livneh's model that influences quality of life outcomes, and the current data supports this hypothesis. While self-efficacy showed a univariate association with employment, this relationship became non-significant in the adjustment model, when physical health was entered as a potential predictor of employment outcome. This finding suggest that self-efficacy has an indirect effect on employment, through physical health. Individuals who have a stronger sense of self-efficacy in managing their diabetes have better health, which in turn leads to better employment outcomes.

Diabetes knowledge was associated with some outcomes at univariate level, but in the multivariable model this measure was not significant in predicting quality of life outcomes. Many individuals have comparable levels of diabetes knowledge, possibly due to their involvement with diabetes education classes. Most information contained in the diabetes knowledge test is communicated to people in diabetes education classes provided through the hospitals, and most individuals master this knowledge without any difficulty. The majority of individuals recruited through mail as well participated in diabetes education classes in the past. Differences on diabetes knowledge were tested between those who did and those who did not participate in these classes (using an independent sample t-test), and none was found when the group means were compared. The diabetes knowledge test had inadequate psychometric properties, and its questionable reliability significantly decreases trust in these results. In turn, the one-item measure asking individuals to identify their level of understanding

of diabetes and its treatment was used as an alternative knowledge component in addition to the 11-item diabetes knowledge test. This variable was found to be associated with certain quality of life outcomes, suggesting that the better individuals understand their condition the better they rank their quality of life, across physical health, psychological well-being and social relationships. A subjective assessment of one's own level of understanding of diabetes and its treatment was associated at univariate level and in the adjusted model as well with physical health, psychological well-being, and social relationships.

5.4 Contributions to Prior Research

In this study it was found that low health literacy is not prevalent in persons with diabetes. Inadequate functional health literacy affects only a small proportion of individuals with diabetes. In comparison to several other studies' participants, the current sample overall performed better on TOFHLA, suggesting better functional health literacy skills. Sample characteristics and instrumentation could explain these findings to some extent.

Several other studies (Baker et al., 1998; Gazmararian, et al., 2003; Williams, et al., 1998) recruited samples from individuals from disadvantaged backgrounds in terms of low health literacy (i.e., elderly, predominantly minorities, individuals with less education). In contrast, participants for this study came from diabetes educational and support groups and from consumer groups of the public vocational rehabilitation agency. This current sample approximates better the general population. One way this sample might be skewed in comparison to other samples and the general population as well is the high level of education of the individuals in the group. Almost 1/3 of current participants, or 31.7% had some college education, without acquiring a degree, and 29.4% had college degree or more education. Only

38.1% had high school degree, GED or less. As a cross-reference for educational attainment, individuals with diabetes who exited the public vocational rehabilitation in fiscal year in 2009 in Michigan were examined. A total of 221 individuals with diabetes were rehabilitated during FY2009. An examination of the level of education of these individuals reveals that the education level of the current sample is considerable higher than the education level of the MRS consumers' who have diabetes. In this group of 221 individuals 69.2% had high school degree, GED or less, 16.7% had some college without earning any degree, and 14.0% had a Bachelor or higher degree. The racial/ethnic composition of MRS customers closed in FY2009 who have diabetes (n=221) is as follows: 50.7% White, 44.3% African American, and the other 5.0% were of some other race/ethnicity. This study's sample however had 61.1% European American, and 27.0% African American. Evidently, there were some marked differences between this sample, other studies sample, and the customers from MRS in terms of educational and racial/ethnic background.

An examination of samples used by other seminal studies on the impact of health literacy on health outcomes reveals that these other studies often times collected data on samples from vulnerable populations as far as low health literacy. For example, 92% of the sample of one study consisted of individuals of African American racial background (Baker et al., 1998), and 86.4% had 12 years of education, while only 13.6% had > 12 years of education. Other studies (Gazmararian et al., 2003; Baker et al., 2004) recruited participants from the 65 years or older age category. In this study, multivariate analysis results indicated that health literacy was independently related to disease knowledge. Also, in another study (Williams et al., 1998) the sample of 114 individuals with diabetes had low education level (68% less than 12 years of education) and almost 90% belong to some minority group. These are the

same groups that are at-risk groups of having low health literacy, such as elderly, low SES groups, females and minorities.

One working hypothesis for the current study was that health literacy is a significant predictor of employment outcomes. The current empirical findings refuted this hypothesis. While current data indicated a small difference between mean literacy scores of employed and not employed individuals, with employed individuals performing higher on the health literacy test, these differences were not statistically significant. According to current findings, there is no statistical dependence between health literacy and employment. This finding is revealing and adds new knowledge to the current vocational rehabilitation literature. Furthermore, could raise additional research questions on intermediary constructs that could reveal indirect associations between functional health literacy and employment outcomes.

In lack of prior research examining the relationship of functional health literacy and employment, the impact of education and general literacy skills on employment outcomes of persons with disabilities could provide a context to discuss current findings. While the National Adult Literacy Survey (Kirsch et al., 2002), in examining the relationship of general literacy level and employment found that individuals with higher level of literacy are more likely to be employed, they also worked more hours and had higher wages, my research specifically looking at the associations of literacy in the health context found no associations between such skills and employment outcomes. It is possible that general literacy skills matter rather than literacy in the health context when it comes to employment outcomes. While it is possible for health literacy and employment not to be associated, skewness in the data might have interfered with the power of the current study to accurately test these associations. Further studies, with a better distribution in the health literacy construct must

be pursued to help answer these questions with more certainty.

Prior research, examining the associations between education and employment in individuals with disabilities is inconclusive. A recently conducted comprehensive meta-analysis discussed determinants of employment for persons with disabilities (Saunders, Leahy, McGlynn, & Estrada-Hernandez, 2009). This study integrated outcome research produced during 25 years in rehabilitation counseling. Researchers examined nearly 200 different independent variables in relation to obtaining or re-gaining employment for persons with disabilities. Of primary interest to current research were findings in relation to the impact of education on employment. While there were no studies looking at health literacy in relation to employment, 22 studies were identified that investigated the relationship of education and employment. Findings were mixed, some studies concluded that college education was an advantage, while others said the opposite, concluding that college education was not associated with employment. Another groups of studies found no relationship between education and successful employment.

General literacy, health literacy and educational attainment are interrelated. More studies, looking at each construct simultaneously could possibly examine their impact, relative importance or possible interaction effect on employment outcomes of persons with disabilities. These references mentioned above can provide a context for discussion, without the certainty of conclusive evidence. Samples and constructs are not identical, which creates serious challenges when trying to draw conclusions on these matters.

The findings indicating no association of health literacy with physical health and psychological well being were somewhat unexpected. These results contradict findings from other research, but are in alignment with some other studies' findings. Many studies indicated

a significant direct association between health literacy and health outcomes. Poor health literacy was found to be associated with poor knowledge of disease, decreased likelihood for using preventive health care services, higher rates of hospitalization, more need for emergency care, less medication adherence, and worse health-management, and communication problems with health care providers (Baker et al., 1998, 2002; Kripalani et al., 2006; Davis et al., 2006; Houts et al., 2001, 1998; Schillinger et al., 2004; Kripalani & Weiss, 2006; Parker & Gazmararian, 2003; Sudore et al., 2009). In terms of psychological well-being, prior research found a significant association between inadequate health literacy and depression (Gazmararian et al., 2000). The odds of experiencing depression was 2.7 for with individuals with inadequate health literacy when compared to individuals with adequate health literacy. Depression is only one dimension of psychological well-being, while the current study used the WHO's Brief Quality of Life Survey instrument, where the psychological well-being domain encompasses more than the lack of depression. In this definition psychological well-being includes the presence of positive feelings and self-esteem, good cognitive functioning and positive body image. A solid reason for such contrasting findings may very much be the differences in the underlying constructs (e.g., hospitalization as a measure of physical health, versus physical health defined as the lack of pain and discomfort, fatigue, having energy, the ease with which relief from pain can be achieved). The lack of full correspondence in operationalization of outcomes could led to differences in findings in comparison to other studies' results.

Diabetes management self-efficacy was found to have a significant impact on each quality of life domain. The current data suggests an indirect connection between self-efficacy and employment through physical health, and a direct association with physical health, psy-

chological well-being and social relationships. This finding aligns to other studies findings, where it has been shown that the belief in one's abilities to carry out health management behaviors has favorable effect on several individual outcomes (Johnson et al., 2006). Higher levels of self-efficacy positively impact health management behaviors such as diet, exercise, blood glucose monitoring, and foot care (Sarkar et al., 2006) in the population of persons with diabetes.

5.5 Implications for Practice

Rehabilitation counseling interventions are targeted toward improved client outcomes across different life domains, such as physical health, psychological well-being, social and interpersonal well-being, financial and material well being, employment and productivity, and functional ability. A better understanding of factors that impact quality of life outcomes could help design more effective rehabilitation interventions based on individualized self-management training to effectively maintain or potentially improve ones quality of life.

Individuals with chronic illness and disability are in ongoing contact with health care providers and the health care system to some degree because of the need to manage their medical condition. These individuals need to quickly identify first signs of changing health status and seek out appropriate resources to help remedy issues and properly adjust.

Level of interference of diabetes with daily living activities had a significant negative impact on all quality of life outcomes studied. Individuals need to develop knowledge and skills to reduce this interference, and effectively manage their health. As current and prior research supports, a healthy sense of self-efficacy is fundamentally important, for someone to optimally negotiate challenges related to own condition.

Diabetes management self-efficacy was found to have an independent direct effect on health, and possibly an indirect effect on employment through health and self-management behaviors. Diabetes management self-efficacy also has a significant positive impact on psychological well-being and social relationships. The ability to self-manage diabetes is associated with individuals confidence in own skills to carry out diabetes self-management activities, such as eating an appropriate diet, getting proper exercise, foot care, checking blood glucose and taking oral medication and insulin. Given that this construct has such a major impact on several quality of life domains, it is important to help individuals develop an optimal level of self-efficacy. Self-efficacy influences health-related choices, health-related goals, self-management behaviors and the amount of effort and perseverance invested to carry out these tasks (Sarkar et al., 2006). Vocational rehabilitation agencies could develop group or individual training activities to help individuals develop or improve their diabetes management self-efficacy, by teaching health management behaviors and providing positive feedback to individuals if tasks are completed successfully.

5.6 Future Research Recommendations

Evidently there is plenty of opportunity to expand or replicate these research findings. One recommendation would be to replicate this study with a novel, more up to date health literacy instrument. TOFHLA has been criticized for testing reading and computational skills only. Previous researchers found that the health aspect and health context is not sufficiently covered in the instrument. A possible future research project could be to develop a new health literacy instrument, that goes beyond individual capacity and incorporates characteristics of the healthcare system as well.

Non-experimental and experimental studies could be employed, to reexamine current findings. Variables such as health literacy, diabetes knowledge, and self-efficacy could be experimentally manipulated and examined in relation to the quality of life outcomes herein investigated. Experimental manipulation would allow for more certainty regarding the causality of these relationships. This way confounds could be more rigorously controlled. Longitudinal studies could be a possibility, before and after diabetes education classes, to assess the impact of the knowledge and skills acquired on diabetes knowledge, and on self-management of health. Longitudinal studies could also be effective in self-efficacy enhancement programs.

Additional studies examining the mechanism connecting health literacy, diabetes management self-efficacy and diabetes knowledge to quality of life outcomes would be of great benefit to understanding determinants of quality of life of this population. Could have great potential to study what specific self-management behaviors are initiated as a result of improved self-efficacy and diabetes knowledge.

Health literacy was found not to be directly associated with any of the four different quality of life outcomes investigated in this study. While a new measure could significantly help improve operationalizing this construct, these improved measures could be used to replicate these findings. If similar results are found, studies could be conceptualized and carried out to examine possible indirect relationships between health literacy and the investigated quality of life domains.

Also, it is important to reach out to groups that are hesitant to participate, and recruit them to be able to get a comprehensive picture of these relationships and generalize the findings to the whole population.

5.7 Conclusions

This study investigated the prevalence of low health literacy and examined whether health literacy skills are related to disparities in health outcomes based on race/ethnicity, SES, and age. Livneh's (2001) quality-of-life-based model was used to examine the relationship between health literacy, self-efficacy and knowledge of CID and four distinct quality of life domains. Four in five (81.7%) respondents had adequate health literacy. In examining whether health disparities in race/ethnicity, SES and age are reflected in health literacy scores, current findings support significant race/ethnicity effects on both reading and numeracy and on overall health literacy as well. There were no differences in health literacy scores based on SES and age. There was a lack of association between health literacy and the quality of life domains investigated. In terms of employment, individuals who worked, performed slightly higher on the health literacy test, but the differences were not statistically significant. Interesting results emerged pertaining associations between diabetes knowledge and diabetes management self-efficacy and quality of life. There was an unadjusted effect of self-efficacy and diabetes knowledge on employment. In the adjusted model, physical health and the level of interference of diabetes with activities of daily living (ADLs) are the main statistically significant independent effects that explain the odds of one being employed. Although high levels of self-reported diabetes management self-efficacy is strongly associated with employment, the causal pathways for this relationship is likely to be through physical health and the lack of interference of diabetes with ADLs. In relation to physical health, the effect of diabetes management self-efficacy holds in the adjusted model as well, supporting the presence of an independent non-redundant effect. Level of understanding of diabetes and its treatment positively affects physical health. These results suggest that individuals

with higher levels of diabetes management self-efficacy, and those who have a better understanding of diabetes and its treatment report better psychological well-being. Diabetes management self-efficacy, level of understanding of diabetes and its treatment, and lack of interference of diabetes with ADLs are significant predictors of social relationships.

Results of current research, tentative to some extent due to limitations stemming from sampling and instrumentation issues, expand our understanding of the relationship between the three process variables studied and the quality of life outcomes. The current sample represents a sub-group of individuals with diabetes, where females and individuals with more education were overrepresented. As such, the results of this research should be confined to this sub-group and should not be generalized to all individuals with diabetes.

Findings from this research have theoretical and practical applications. Livneh's theory was partially supported by current findings, and these outcomes could also be used in clinical practice. This data supports the importance to design psychoeducational interventions to improve self-management of one's disability or chronic condition while receiving vocational rehabilitation services. These interventions should incorporate diabetes knowledge and self-efficacy training, which competencies seem to considerably impact different quality of life domains.

APPENDICES

Appendix A

LETTER OF INFORMED CONSENT (USED WITH ALL BUT PARTICIPANTS
RECRUITED THROUGH SAINT JOSEPH MERCY HEALTH SYSTEM)

Informed Consent

Purpose of research: You are being asked to participate in a research study that aims to investigate the influence of health literacy on the quality of life of persons with diabetes. Health literacy, the ability to understand, process and act on health information is very important for health outcomes. This study investigates the role of this knowledge on other quality of life domains, specifically employment, and psychosocial functioning. The importance and immediacy of this study cannot be sufficiently stressed given the high prevalence of diabetes and the high risk of complications if it is not properly treated. A better understanding of factors that influence health management and quality of life of individuals with diabetes is important. Knowledge gained from this study could be used in designing interventions for more efficient management of diabetes and prevention of complications.

What you will do: All you need to do is to complete a series of questionnaires that will take approximately 30 minutes. The test packet includes the Test of Functional Health Literacy for Adults, the World Health Organization Quality of Life Survey, a Perceived Diabetes Self Management Scale, A Diabetes Knowledge test, and a brief section asking about your employment and demographic data.

Confidentiality: The data for this project are being collected anonymously. Neither the researchers nor anyone else will be able to link data to you. Each survey will be assigned a case number, and names or other personal identifiers will not be asked in the questionnaires. Data will be stored for a period of 3 years after the completion of this research on password protected computers on MSU campus. Data will remain confidential including both paper and computer-stored records.

Risks and benefits: Your participation in this study may contribute to the understanding

of factors that could influence health management of diabetes, and ultimately impact quality of life of people living with this condition. There are no foreseeable risks associated with participation in this study. You are free at any time to stop participating in this study. There will be no negative consequences in withdrawing participation.

Costs and compensation for being in the study: You will be paid \$10 for your participation. Taking part is voluntary: Please note that your participation in this project is voluntary and you have the right to skip any question(s) you do not want to answer. In addition, you may discontinue at any time.

Contact information for questions and concerns: If you have concerns or questions about this study please contact Dr. Michael J. Leahy through regular mail at Michigan State University, 463 Erickson Hall, East Lansing, MI 48824, or email at leahym@msu.edu or by phone at (517) 432-0605. If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or e-mail irb@msu.edu or regular mail at 207 Olds Hall, MSU, East Lansing, MI 48824.

Documentation of informed consent: Your signature below means that you voluntarily agree to participate in this research study.

Signature

Date

Appendix B

LETTER OF INFORMED CONSENT (USED WITH PARTICIPANTS RECRUITED
THROUGH SAINT JOSEPH MERCY HEALTH SYSTEM)

St. Joseph Mercy Health System

Consent to Participate in Research

You are being asked to participate in a research study that aims to investigate the influence of health literacy on the quality of life of persons with diabetes. Health literacy, the ability to understand, process and act on health information is very important for health outcomes. This study investigates the role of this knowledge on other quality of life domains, specifically employment, and psychosocial functioning. The importance and immediacy of this study cannot be sufficiently stressed given the high prevalence of diabetes and the high risk of complications if it is not properly treated. A better understanding of factors that influence health management and quality of life of individuals with diabetes is important. Knowledge gained from this study could be used in designing interventions for more efficient management of diabetes and prevention of complications.

If you decide to participate, you will be asked to complete a series of questionnaires that will take approximately 30 minutes. You will be paid \$10 for your participation.

The data for this project are being collected anonymously. Neither the researchers nor anyone else will be able to link data to you. Each survey will be assigned a case number, and names or other personal identifiers will not be asked in the questionnaires. Data will be stored for a period of 3 years after the completion of this research on password protected computers at Michigan State University. Data will remain confidential including both paper and computer-stored records.

Your participation in this study may contribute to the understanding of factors that could influence health management of diabetes, and ultimately impact quality of life of people

living with this condition. There are no foreseeable risks associated with participation in this study.

Please note that your participation in this project is voluntary and you have the right to skip any question(s) you do not want to answer. You may discontinue your participation at any time. You will not be penalized or lose benefits that you would normally be entitled to if you refuse to participate or decide to stop participating in the study.

If you agree to participate, you must be given a signed copy of this document and a written summary of the research.

You may contact Eniko Rak, Principal Investigator, by phone at 517-402-0897 any time you have questions about the research. You may contact the SJMHS Institutional Review Board Coordinator, at 734-712-5470 if you have questions about your rights as a research participant.

Signing this document means that the research study has been described to you, you have had all your questions about the study answered, and that you voluntarily agree to participate.

Printed Name of Participant

Signature of Participant/Date

Signature of Person Providing Information/Principal Investigator/Date

Appendix C

ADVERTISEMENT FLYER

YOU ARE INVITED

to Participate in a Research Study

Health Literacy and Quality of Life in Persons with Diabetes

Purpose of research: This research seeks to understand the relationship between your Health Knowledge and specific aspects of your life (Employment, Health and Social Functioning).

Eligibility criteria: individuals older than 18 who diabetes.

If you decide to participate, you'll be asked to fill out surveys that will require approximately 30 minutes of your time.

Payment: You will receive \$10 for your participation.

Benefits: Results of this study could be used to help people like you to be more successful in their management of diabetes and improve some aspect of their lives.

Important: Please note that this research is not a requirement for your clinic care by your physician at Michigan State Adult Medicine or by Michigan State University. The data for this project are being collected anonymously. Nobody will be able to link data to you. Each survey will be assigned a case number, and names or other personal identifiers will not be asked. The data collected will not be entered into your medical records.

If you want to participate, please call or email:

Eniko Rak
Doctoral Student
Michigan State University

517-402-0897
rakeniko@msu.edu

Appendix D

INSTRUMENTS

TOFHLA (N)

Please answer questions 1 through 17 on the blank line provided after the question:

These are directions you or someone else might be given at the hospital. Please read each direction to yourself then answer the questions that follow about what it means.

GARFIELD IM	16 Apr 93
FF941858 Dr. LUBIN, MICHAEL	
PENICILLIN VK	
250 MG 40/0	
Take one tablet by mouth four times a day	
02	(4 of 40)

1. If you take your first tablet at 7:00 a.m., when should you take the next one?

2. And the next one after that?

3. What about the last one for the day, when should you take that one?

Have a look at this one:

GARFIELD IM	16 Apr 92
FF941861 Dr. LUBIN, MICHAEL	
AMIOXICILLIN LIQ	
125MG/5ML 15OML1/0	
Refrigerate-Shake well; discard after March 15, 1993	
02 12	(1 of 1)

4. Could you take that medicine on July 10, 1993?

Here is another direction you might be given:

GARFIELD IM	16 Apr 93
FF941860 Dr. LUBIN, MICHAEL	
METHOTREXATE	
2.5MG	10/0
Take every third day.	
08 11 14 31	(1 out of 10)

5. If you began taking your medicine Tuesday, when should you take it next?

6. What day would you take it after that?

7. **Normal blood sugar is 60 – 150. Your blood sugar today is 160.** If this were your score, would your blood sugar be normal today?

Have a look at this one:

CLINIC APPOINTMENT		
CLINIC: Diabetic	LOCATION: 3 rd floor	
DAY: Thurs.	DATE: April 2 nd	HOUR: 10:20 am pm
Issued by		
YOU <u>MUST</u> BRING YOUR PLASTIC CARD WITH YOU		

8. When is your next appointment?

9. Where should you go?

Have a look at this one:

GARFIELD IM	16 Apr 93
FF941860 Dr. LUBIN, MICHAEL	
TETRACYCLINE	
250 MG	40/0
Important: Finish all this medication unless otherwise directed by prescriber	
02 03 04 11 31	(4 of 40)

10. How many of those pills should you take?

Have a look at this one:

GARFIELD IM	28 Dec 92
FF941857 Dr. LUBIN, MICHAEL	
PHENOBARBITAL	
30 MG	90/2
After two refills or six months from date of issue, this prescription can only be refilled by authority of physician. (2 refills)	
01 08	(9 of 90)

11. How many times can you get that prescription refilled?

12. When is the date of issue?

13. When is six months from the date of issue?

Have a look at this one:

GARFIELD IM	16 Apr 93
FF941862 Dr. LUBIN, MICHAEL	
DOXYCYCLINE	
100 MG	20/0
Take medication on empty stomach one hour before or two to three hours after a meal unless otherwise directed by your doctor.	
02 11	(0 of 20)

14. If you eat lunch at 12:00 noon, and you want to take this medicine before lunch, what time should you take it?

15. If you forgot to take it before lunch, what time should you take it?

16. **For clinic care, you only must apply once each six months.** Let's just say the last time you came to the clinic was on July 12, 1992. When would you have to reapply for financial aid?

Have a look at this one:

You can get at no cost if after deductions your monthly income and other resources are less than:

\$ 581 for a family of one	\$ 1,196 for a family of four
\$ 786 for a family of two	\$ 1,401 for a family of five
\$ 991 for a family of three	\$ 1,606 for a family of six.

17. Let's say that after deductions, your monthly income and other resources are \$1,129. And let's say you have three children. Would you have to pay for your care at that clinic?

TOFHLA (R)

Instruction: Here are some other medical instructions that you or anybody might see around the hospital. These instructions are in sentences that have some of the words missing. Where a word is missing, a blank line is drawn, and 4 possible words that could go in the blank appear just below it. I want you to figure out which on those 4 words should go in the blank, which word makes the sentence make senses. When you think you know which one it is, circle the letter in front of that word, and go on the next one. When you finish the page, turn the page and keep going until you finish all the pages.

PASSAGE A

Your doctor has sent you to have a _____ X-ray.

- a. stomach
- b. diabetes
- c. stitches
- d. germs

You must have an _____ stomach when you come for _____.

- | | |
|-----------|--------|
| a. asthma | a. is. |
| b. empty | b. am. |
| c. incest | c. if. |
| d. anemia | d. it. |

The X-ray will _____ from 1 to 3 _____ to do.

- | | |
|---------|-----------|
| a. take | a. beds |
| b. view | b. brains |
| c. talk | c. hours |
| d. look | d. diets |

THE DAY BEFORE THE X-RAY.

For supper have only a _____ snack of fruit, _____ and jelly,

- | | |
|-----------|-----------|
| a. little | a. toes |
| b. broth | b. throat |
| c. attack | c. toast |
| d. nausea | d. thigh |

with coffee or tea.

After _____, you must not _____ or drink

- | | |
|--------------|----------|
| a. minute, | a. easy |
| b. midnight, | b. ate |
| c. during, | c. drank |
| d. before, | d. eat |

anything at _____ until after you have _____ the X-ray.

- | | |
|---------|--------|
| a. ill | a. are |
| b. all | b. has |
| c. each | c. had |
| d. any | d. was |

THE DAY OF THE X-RAY.

Do not eat _____.

- a. appointment.
- b. walk-in.
- c. breakfast.
- d. clinic.

Do not _____, even _____.

- | | |
|-----------|------------|
| a. drive, | a. heart. |
| b. drink, | b. breath. |
| c. dress, | c. water. |
| d. dose, | d. cancer. |

If you have any _____, call the X-ray _____ at 616-4500.

- | | |
|---------------|---------------|
| a. answers, | a. Department |
| b. exercise, | b. Sprain |
| c. tracts, | c. Pharmacy |
| d. questions, | d. Toothache |

PASSAGE B

I agree to give correct information to _____ if I can receive Medicaid.

- a. hair
- b. salt
- c. see
- d. ache

I _____ to provide the county information to _____ any

- | | |
|----------|--------------|
| a. agree | a. hide |
| b. probe | b. risk |
| c. send | c. discharge |
| d. gain | d. prove |

statements given in this _____ and hereby give permission to

- a. emphysema
- b. application
- c. gallbladder
- d. relationship

the _____ to get such proof. I _____ that for

- | | |
|-----------------|----------------|
| a. inflammation | a. investigate |
| b. religion | b. entertain |
| c. iron | c. understand |
| d. county | d. establish |

Medicaid I must report any _____ in my circumstances

- a. changes
- b. hormones
- c. antacids
- d. charges

within _____ (10) days of becoming _____ of the change.

- | | |
|----------|----------|
| a. three | a. award |
| b. one | b. aware |
| c. five | c. away |
| d. ten | d. await |

I understand _____ if I DO NOT like the _____ made on my

- | | |
|---------|---------------|
| a. thus | a. marital |
| b. this | b. occupation |
| c. that | c. adult |
| d. than | d. decision |

case, I have the _____ to a fair hearing. I can _____ a

- | | |
|-----------|------------|
| a. bright | a. request |
| b. left | b. refuse |
| c. wrong | c. fail |
| d. right | d. mend |

hearing by writing or _____ the county where I applied.

- a. counting
- b. reading
- c. calling
- d. smelling

If you _____ TANF for any family _____, you will have to

- | | |
|----------|--------------|
| a. wash | a. member, |
| b. want | b. history, |
| c. cover | c. weight, |
| d. tape | d. seatbelt, |

_____ a different application form. _____, we will use

- | | |
|-----------|-------------|
| a. relax | a. Since, |
| b. break | b. Whether, |
| c. inhale | c. However, |
| d. sign | d. Because, |

the _____ on this form to determine your _____.

- | | |
|-----------|-------------------|
| a. lung | a. hypoglycemia. |
| b. date | b. eligibility. |
| c. meal | c. osteoporosis. |
| d. pelvic | d. schizophrenia. |

PASSAGE C

It has been explained to _____ that during the course of the

- a. my
- b. me
- c. he
- d. she

_____ or procedure, unforeseen conditions may be _____

- | | |
|--------------|--------------|
| a. syphilis | a. revealed |
| b. hepatitis | b. depressed |
| c. colitis | c. directed |
| d. operation | d. notified |

that necessitate an extension of the _____ procedure (s) or

- a. appendix
- b. another
- c. original
- d. addict

different procedure (s) than those _____ forth in paragraph 2.

- a. get
- b. set
- c. see
- d. go

I therefore, _____ and request that the above named

- a. exercise
- b. authorize
- c. energize
- d. pressurize

_____, his assistants or attending physicians _____ such

- | | |
|---------------|------------|
| a. infection, | a. perform |
| b. pregnant, | b. smear |
| c. insurance, | c. onset |
| d. physician, | d. stress |

procedure as are necessary and _____ in the exercise of professional judgment.

- a. undesirable
- b. emergency
- c. desirable
- d. diagnosis

The authority _____ under this Paragraph 3 shall _____

- | | |
|------------|------------|
| a. granted | a. pretend |
| b. treated | b. extend |
| c. tested | c. recede |
| d. X-rayed | d. proceed |

to treating all conditions that _____ treatment and are not known

- a. reason
- b. refer
- c. require
- d. relate

_____ the time the operation or _____ is commenced.

- | | |
|-------|----------------|
| a. us | a. cholesterol |
| b. be | b. menopause |
| c. or | c. gonorrhoea |
| d. at | d. procedure |

WHOQOL-BREF

Instructions: This questionnaire asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks. Please read each question, assess your feelings, and circle the number on the scale that gives the best answer for you for each question.

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4.	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	Slightly	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor well	Well	Very well
15.	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with your abilities?	1	2	3	4	5
20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your mode of transportation?	1	2	3	4	5

The follow question refers to how often you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	1	2	3	4	5

EMPLOYMENT INFORMATION

Did you do any paid work in the past?

Yes No

What was your hourly wage on your last job? _____

How many hours were you working a week on your last job? _____

What is your current employment status?

Employed full-time Employed part-time Not working

What is your occupation? _____

On average, how many hours do you work in a week? _____

What is your hourly pay? _____

Do you have benefits?

Yes

No

If yes, please describe: _____

How do you feel about your current work?

Not at all satisfied

Not satisfied

Satisfied

Very satisfied

How do you feel about having a job in the next year?

Very confident

Fairly confident

Not very confident

Not at all confident

I do not want a job

Do not know

Welfare status

On welfare during past year

On welfare, but not during past year

Never on welfare

PDSMS

		Strongly disagree	Disagree	Neither agree, nor disagree	Agree	Strongly agree
1.	It is difficult for me to find effective solutions for problems that occur with managing my diabetes.	1	2	3	4	5
2.	I find efforts to change things I don't like about my diabetes are ineffective.	1	2	3	4	5
3.	I handle myself well with respect to my diabetes.	1	2	3	4	5
4.	I am able to manage things related to my diabetes as well as most other people.	1	2	3	4	5
5.	I succeed in the projects I undertake to manage my diabetes.	1	2	3	4	5
6.	Typically, my plans for managing my diabetes don't work out well.	1	2	3	4	5
7.	No matter how hard I try, managing my diabetes doesn't turn out the way I would like.	1	2	3	4	5
8.	I'm generally able to accomplish my goals with respect to managing my diabetes.	1	2	3	4	5

CID KNOWLEDGE: DIABETES

True or False (Circle the right answer)

1. Normal blood sugar is between 70 and 140	T	F
2. If you feel thirsty, tired, and weak, it usually means your blood sugar is high	T	F
3. The best time to take insulin or diabetes pills is 15–30 min before a meal	T	F
4. Insulin and diabetes pills make your blood sugar go down	T	F
5. A person with diabetes check their feet for blisters or sore spots every day	T	F
6. When you exercise, your blood sugar goes down	T	F
7. If you feel shaky, sweaty, and hungry, it usually means your blood sugar is low	T	F
8. If you suddenly get sweaty, nervous and shaky, you should eat some form of sugar	T	F
9. If diabetes is not well controlled, it can injure both kidneys and nerves	T	F
10. You should get your eyes checked every year	T	F
11. If you wake up in the morning, and you feel sick to your stomach and do not want to eat, you should take half of the usual dose of medicine	T	F

BACKGROUND INFORMATION

Gender: Female Male

Race/Ethnicity

Non-Hispanic White	Native American
African American	Multiracial
Hispanic	I prefer not to answer
Asian/Pacific Islander	

How old are you? _____ years old

What is the highest level of education that you have completed?

No formal education	High school degree or GED
Less than eight grade	Some college, no degree
Some high school, no degree	College degree or more

What is the total annual net income of all persons living in your household?

\$20,000 or less	\$80,001 - \$100,000
\$20,001 - \$40,000	More than \$100,000
\$40,001 - \$60,000	I don't know
\$60,001 - \$80,000	I prefer not to answer

How many people live in your household? _____ people (including yourself)

Language: Nonnative English speakers Native English speakers

Which type of diabetes did your doctor say that you have?

type 1 (insulin-dependent or juvenile diabetes)
type 2 (non insulin-dependent or adult onset diabetes)
Other: _____

How long ago were you told by a doctor that you had diabetes?

Recently (less than 1 year ago)	More than 5 years ago
A few years ago (2 – 5 years)	At birth

How often does your diabetes prevent you from doing your normal daily activities (ex. work)? Circle one number.

Never 2 3 4 5 6 Frequently

1

7

Did you ever go to diabetes patient education program?

Yes

No

Attending one right now

How would you rate your understanding of diabetes and its treatment? Circle one number.

Poor

Excellent

1

2

3

4

5

6

7

Are you now taking diabetes pills? Yes No

Are you now taking insulin? Yes No

What is your height? _____ feet _____ inches

How much do you weigh? _____ pounds

Do you have health insurance? Yes No

Who pays for your insurance?

Employer

Military

Self

Medicare

Medicaid

What sources do you use for health information?

None

A little

Some

A lot

Newspaper	1	2	3	4
Magazines	1	2	3	4
Books	1	2	3	4
Brochures	1	2	3	4
Internet	1	2	3	4
Television	1	2	3	4

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