

## CHAPTER 1

### INTRODUCTION

#### **Statement of the problem**

Diabetes is a chronic health problem with devastating, yet preventable consequences. It is characterized by high blood glucose levels resulting from defects in insulin production, insulin action, or both.<sup>1,2</sup> Globally, rates of type 2 diabetes were 15.1 million in 2000,<sup>3</sup> the number of people with diabetes worldwide is projected to increase to 36.6 million by 2030.<sup>4</sup> In 2007, 23.6 million people, or 7.8% of the United States population had type 2 diabetes. Of these, 90-95% of these cases were adults with type 2 diabetes. Type 2 diabetes impacts men and women proportionately; there are over 12 million men with diabetes and 11.5 women with diabetes. In adult patients, 6.6% were non Hispanic White, 11.8% were non Hispanic Black, 10.4% were Hispanic, and 7.5% were Asian.<sup>1</sup> This rate is expected to increase greatly over the next half-century. Along with the increase in incidence of diabetes, both individual and societal expectations concerning the management of diabetes have also increased, with many reports from The Centers for Disease Control (CDC), United States Department of Health and Human Services (USDHHS), and the

National Institutes of Health (NIH) urging patients to “Take Charge of Your Diabetes”<sup>5</sup> and “Conquer Diabetes”.<sup>6</sup> One of the main goals of USDHHS’s report, Healthy People 2010, is to improve the quality of life for persons with diabetes.<sup>7</sup>

Taking control of diabetes to improve quality of life has put the spotlight on the need for additional support and education for patients with type 2 diabetes. Although new treatments and technology have aided in controlling the disease in many individuals, the challenges of diabetes self-management are overwhelming for most. Diabetes is a chronic disease for which control of the condition demands patient self-management.<sup>8-10</sup> Self-management behaviors include monitoring blood glucose levels, taking medication, maintaining a healthy diet and regularly exercising. For most patients, it is important to conduct daily foot exams. However, despite the technological and scientific advances made toward the treatment of diabetes, the American Association of Clinical Endocrinologists reports that only 1 in 3 patients with type 2 diabetes is well controlled.<sup>11</sup> Only about one-third of patients report adherence to monitoring blood glucose levels.<sup>12</sup> The American Association of Diabetes Educators suggest that only one-half of patients adhere to medication.<sup>13</sup> There are relatively high levels of non-adherence in all areas of self-management behaviors. This non-adherence is perhaps due to the fact that self-management behaviors usually require changes in the patient’s daily life. In order to successfully make these changes, patients opt or are encouraged by others to set goals to make the incremental changes necessary to create life-long habits that allow them to manage their diabetes.<sup>8,14</sup>

Goal setting and the support and feedback that a support group provides can significantly improve the chances of achieving self-management goals in persons with type 2 diabetes. Diabetes peer support groups are a valuable source of diabetes information and link patients together to provide mutual support. Such groups can be an integral facilitator to improving the relationship between identifying with diabetes and setting diabetes-specific self-care goals.<sup>15</sup> Affiliated with diabetes clinics, managed care organizations or professional associations such as the American Diabetes Association<sup>16</sup>, support groups can be face-to-face or online. Online groups allow patients with type 2 diabetes to engage with one another and exchange information, education and advice with other patients, clinicians and researchers in real time and at any time.<sup>17-19</sup> Being a part of the group also makes one more accountable and motivated to achieve personal goals that then improve the status of the group. Collaborative goal setting is valuable to improve self-management skills.<sup>8</sup>

Online support groups have been shown to aid in goal setting and self-management skills.<sup>20-22</sup> Daily Strength® ([www.dailystrength.org](http://www.dailystrength.org)), an online type 2 diabetes support group allows individual members to list personal goals, quantifying the goal by setting a time frame and an achievable metric and then tracks the individual's progress toward meeting the goal. Other group members can provide feedback and encouragement, challenge the individual to set higher goals and join them by setting similar goals. Members of the group might have varying goals, however, the common goal of the group is to successfully manage diabetes by providing support and encouragement to all members. Individuals

who do not belong to such groups might lack the necessary level of support and motivation to set and achieve personal goals.<sup>10,23</sup>

Self-management of diabetes requires time and activities (i.e. monitoring blood-glucose levels) that can attract the attention of others. However, when the patient is effectively managing the condition, outwardly he might appear healthy. Daily decision making in diabetes can have direct implications for health, however many daily self-care activities are aimed at achieving maintenance of acceptable standards that are necessary to prevent long term complications. It is also important to note that a diminished self or loss of self can result from the loss of alternative social identities due to the pervasive nature of diabetes.<sup>24</sup> Diabetes can influence everyday social interactions in many ways; the patient must restrict the types and amounts of foods they ingest, they might have to monitor their blood glucose levels at specific times during the day, and medication might be necessary at times when the individual is engaged in social activities.<sup>25</sup>

Chronic illness and the management of symptoms can influence social relationships, and can create identity problems that the individual must struggle with.<sup>24,26-29</sup> As such, many patients with diabetes have sought support from fellow diabetes patients to ease the strain of the illness. Participating in a diabetes support group is one way that patients can increase the odds for implementing self-management behaviors. For these reasons, patients with type 2 diabetes that participate in support groups will be examined in this study. The mechanism of support and identification with illness on the setting and

achievement of self-management behaviors are the primary relationships that will be assessed.

Other research has focused on the cumulative effect of attitudes, preferences and conceptualizations in the form of identity, measuring the impact identification with the illness has on social relationships with others, including health care providers, and how this identity can influence certain behaviors.<sup>24,26,27</sup> However, these existing studies do not sufficiently examine the role of the support group in goal setting for diabetes self-management behaviors and the achievement of such goals. Utilizing social identity theory, as a basis for understanding the relationship between identity and behavior, this study will examine the influence of identity and participation in support groups on goal setting and goal achievement in patients with type 2 diabetes.

### **Nature of the research project**

This dissertation research is a theory based cross-sectional study using a patient self-administered questionnaire. The exploration of the relationships between support group participation and goal behavior is guided by Social identity theory. The survey instrument was pilot-tested in a group of approximately 15 type 2 diabetes patients in both a pharmacist-conducted UM diabetes care clinic and an online diabetes support group. A clinical pharmacist identified eligible patients through counseling services she provided to the patients. Patients that agreed to participate in the survey completed informed consent forms and some provided feedback on items found on the survey instrument. The instrument included measures of social identity, illness identity,

support group participation, goal setting, goal self-efficacy and the achievement of self-management behavioral goals. The instrument was refined as needed based upon respondent feedback before being pretested in a subset of the study population.

The pretest study population (n=100) included patients in online support groups and those that are not. Participants were selected using Zoomerang®, an online survey tool. Zoomerang® has a respondent panel that included patients that have type 2 diabetes and potentially use online support technology for diabetes peer support. Using the inclusion/exclusion criteria for the study, along with some screening questions, the panel respondents were sorted into two groups: type 2 diabetes patients that belong to an online support group and type 2 diabetes patients that do not belong to a support group. Eligible panel respondents were given a link to complete the survey. Non-responders received reminder emails. Upon completion, respondents received an incentive through Zoomerang®.

Due to the results of the pretest and the difficulty recruiting online support group members through the Zoomerang® panel, the test phase patient recruitment process was altered. Additional non-support group members (n=166) were again recruited through Zoomerang® using the same process as in the pretest phase. Online support group members (n=122) were recruited through various online support group forums through by securing site administrator permission to post a link to the survey hosted on Zoomerang®. All survey data for both groups was collected and stored by Zoomerang®. The data

was analyzed using both exploratory and confirmatory factor analysis, descriptive statistics, and structural equation modeling.

## **Theoretical Background**

There is currently a large body of supporting literature which states that setting performance goals has a positive effect on individuals and groups, particularly in the workplace.<sup>30-33</sup> Identity theories have been used to examine organizational behavior in the workplace by studying group cohesion, decision making, work motivation and performance, leadership, turnover and mergers. One such theory, social identity theory, examines when and why individuals identify with, and behave as part of, social groups.<sup>34-36</sup> Social identity theory explains identity in relation to categories or groups and identity is formed by either self-categorization or identification with groups. Self-esteem and self-efficacy are processes that occur when identity is activated.<sup>37-40</sup> Feelings of confidence and a positive outlook is essential to not only set self-management goals, but to achieve them as well.

Theories about why peer support groups are generally effective include the notion that such groups provide information, and opportunities for social comparison, emotional support, and the expression of feelings.<sup>41</sup> Patients often use support groups when they find themselves in novel stressful situations that cause uncertainty about feelings, thoughts and behaviors.<sup>41</sup> Subjective uncertainty results when contextual factors influence an individual's cognitions, feelings and behaviors, bringing uncertainty to the self. In order to become more

certain, individuals communicate with others to reduce uncertainty, seeking information from others and the environment.<sup>39</sup>

The role of support groups in the identity formation process is in fostering the social comparison that occurs during the self-categorization process. This is also the motivational mechanism found in social identity theory. Social categorizations are based upon social comparisons. Social comparison principles state that in times of distress, individuals will compare themselves with others to evaluate their feelings and abilities.<sup>42</sup> This comparison can be upwards and the individual will compare themselves with someone that they perceive as “better off” to initiate self-improvement behaviors. Downward comparisons are often done to enhance self-esteem by comparing oneself to someone that is perceived as “worse off”. This can also negatively impact the comparator by inducing feelings of anxiety over their own potential for decline. The social comparison process that occurs between support group members has not been thoroughly assessed.<sup>41</sup>

Social identity theory also examines group identification with social groups. Group identification has been found to be positively related to job performance and greater levels of motivation to exert effort on behalf of the group was found in individuals who focus on their own personal self-interest.<sup>43</sup> This may be a result of experiencing the groups’ interests as one’s self-interest in a social respect, if not a personal respect. Identification with a group can result in individuals perceiving themselves more in terms of the traits they have in common with members of the groups they belong to than the traits that

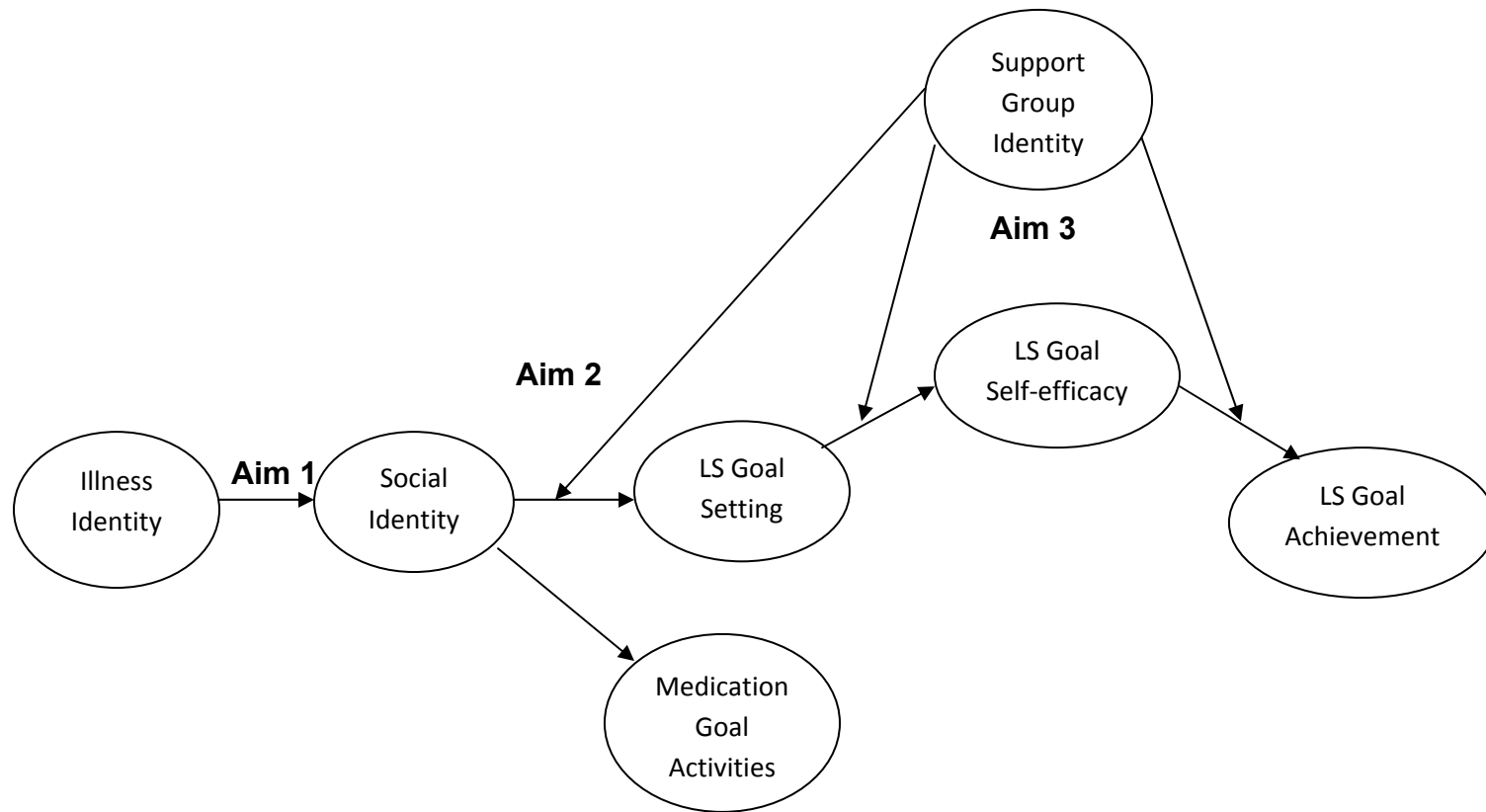


differentiated them from others.<sup>44</sup> This identification process then lessens the difference between the self and the group, allowing the individual to psychologically incorporate the group, and group goals, into their identity.<sup>45</sup> Group “oneness” influences individuals within the group to take the group perspective as their own, and allow them to experience the collective group goals and interests as their own.<sup>46</sup> As such, identification with the group can induce motivation to achieve group goals.<sup>30</sup> There is currently a large body of supporting literature that state setting performance goals has a positive effect on individuals and groups.<sup>47</sup>

Group membership can also make one more accountable, and thus more motivated to achieve personal goals that then improve the status of the group. Daily Strength®, an online type 2 diabetes support group allows individual members to list personal goals, quantifying the goal by setting a time frame and an achievable metric and then tracks the individual’s progress toward meeting the goal. Other group members can provide feedback and encouragement, challenge the individual to set higher goals and join them by setting similar goals. Members of the group might have varying goals; however, the common goal of the group is to successfully manage diabetes by providing support and encouragement to all members. Individuals who do not belong to such groups might lack the necessary level of motivation and accountability to set and achieve personal goals. Through goal setting, support groups can be a source of positive identity information, motivating one to engage in behaviors. This may occur because an individual wishes to improve status (i.e. become known as a

“compliant patient”). Or individuals believe they are a member of a high status group (patients in control of their condition) or are a high-status member of the group (the go-to person for advice, the person with the most experience, etc.). The role of the support group in increasing the self-esteem and self-efficacy of persons with type 2 diabetes to not only set but achieve self-management goals is one focus of this study.

**Figure 1.1: Conceptual model of the relationships between identity, support group identity, goal setting and goal achievement**



### **Components of Social Identity Theory:**

The framework of the dissertation is shown in Figure 1.1. A conceptual framework was constructed for the study and to help visualize the relationships between the constructs that were being measured. The proposed conceptual framework suggests that illness identity, as measured by acceptance of the diabetes diagnosis will influence the patient's social identification with his illness. The framework also links social identity with goal setting and the literature for organizational performance lends some support to the relationship by positing that setting group goals enhances social identity salience and increases group identification as well as the motivation to perform well to achieve goals.

By socially identifying with diabetes, the individual who participates in a type 2 diabetes support group will be more likely to be cognizant of goal setting that may be occurring within the group on an individual basis, but also among members of the group as they strive to meet personal goals and challenge one another to achieve goals. There is currently a large body of supporting literature that state setting performance goals has a positive effect on individuals and groups.<sup>47</sup> The mechanism of support and identification with illness on goal setting and goal achievement are the primary relationships that will be assessed. It is the hope that this research will be able to provide an understanding regarding the social benefit of support groups on goal setting and goal achievement. Guided by the theory of social identity, several hypotheses are proposed to achieve the study objectives.

## Study Aims

The main purpose of this study is to explain and evaluate the influence of support groups and identity on goal setting and achievement in persons with type 2 diabetes. Thus the aims of the study are:

- 1) to determine the relationship between illness identity and social identity on goal setting and achievement in persons with type 2 diabetes.
- 2) to determine the influence of support group identity on the relationship between social identity and goal setting in persons with type 2 diabetes.
- 3) to determine the influence of support group identity on the relationship between goal setting and goal achievement.
- 4) to characterize the interactions that occur within the support group network and use these findings to hypothesize relationships between these interactions and the benefits from such interactions on goal setting.

## Significance

Support has been assessed in many different ways. There is literature examining the effects of peer support in patients with diabetes in a face-to-face setting<sup>10,23,48</sup>, and using telephonic interventions.<sup>49</sup> The role of support groups for patients with chronic illness has also been studied in the virtual world<sup>16,17,20-22,50</sup> and more specifically for patients with diabetes.<sup>18-19,51-52</sup> The majority of these studies confirm that peer support, particularly in a group setting is beneficial to the patient in terms of improving knowledge about diabetes and how to manage the condition, as well as general positive response to the interactions with other patients, however there is no concrete evidence that support group participation improves goal setting and self-management. Goal setting has been studied in patients with type 2 diabetes.<sup>8,15,53</sup> These studies demonstrated that

collaborative goal setting, either with a health care provider<sup>8</sup>, using interactive technology<sup>15</sup> or in conjunction with a diabetes education program<sup>53</sup>, was an effective means to improve self management of diabetes. This study will examine the role of the support group in the goal setting and achievement process by comparing level of participation in such groups with goal behavior.

Social identity theory has proven useful in examining goal behavior in other types of groups, including those online.<sup>54</sup> The role of the group as a source of positive identity that motivates the goal setting and achievement process by improving self-esteem and self-efficacy has not been studied. If support groups are found to be instrumental in the setting and achievement of self-management goals, this research will have implications for the delivery of health care for patients with type 2 diabetes. Peer groups are a cost-effective means to provide patient support on an as-needed basis depending on the patient's needs. For most individuals, online support groups are an easily accessible means of providing information and support continuously at a reasonable cost to an unlimited number of patients. By improving self-management of the condition, these groups also relieve the burden of providing costly treatment and services, such as dialysis and amputation, to patients that do not have their diabetes controlled.

## Hypotheses

Guided by the theory of social identity, several hypotheses are proposed to achieve the study aims.

**Aim 1: To determine the relationship between illness identity and social identity on goal setting and achievement in persons with type 2 diabetes.**

**Hypothesis 1.1:** For individuals with diabetes, illness identity influences one's social identity.

**Hypothesis 1.2:** The association between illness identity and social identity is greater in individuals that belong to an online diabetes support group than those that do not.

**Hypothesis 1.3:** Social identity influences both lifestyle and medication goals.

**Hypothesis 1.4:** Social identity is positively associated with an increase in goal self-efficacy.

**Hypothesis 1.5:** The relationship between goal setting and goal achievement is mediated by goal self-efficacy.

**Aim 2: To determine the influence of support group identity on the relationship between social identity and goal setting in persons with type 2 diabetes.**

**Hypothesis 2.1:** The positive association between social identity and goal setting becomes stronger as the level of support group identity increases.

**Aim 3: To determine the influence of support group identity on the relationship between goal setting and goal achievement.**

**Hypothesis 3.1:** The positive association between goal setting and goal achievement becomes stronger as the level of support group identity increases.

**Hypothesis 3.2:** The level of support group identity increases patient's goal-related self-efficacy and thus strengthens the association between goal setting and goal achievement. As self-efficacy increases, goal achievement increases.

**Aim 4: determine the influence of support group identity on the relationship between goal setting and goal achievement.**

## Notes to Chapter 1

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## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **Chapter Overview**

In this chapter, the scientific literature will be reviewed to increase the understanding of the health problem studied, the theoretical framework for the research questions and the empirical evidence for the study framework. The first section of this chapter provides an overview of the epidemiology of diabetes. In this section, the prevalence of diabetes and its complications will be reviewed. The second section provides an explanation of and the relationship between the key theoretical constructs in the conceptual framework of the study. In section three, the major theoretical approaches to this problem are discussed and several behavioral theories and models are reviewed, and the strengths and limitations of these theories and models are addressed. The last section of the chapter synthesizes the empirical evidence and theories to develop a framework for the study. The rationale for the use of such theories is presented as well.

#### **The Incidence of Diabetes**

Historically, achievements in public health over the 20<sup>th</sup> century have shifted the focus from communicable diseases to chronic diseases such as diabetes. Globally, rates of type 2 diabetes were 151 million in 2000.<sup>1</sup> In

North America, 14.2 million people had type 2 diabetes in the year 2000, and that number is expected to increase 23% to 17.5 million people by the year 2010.<sup>1</sup> In 2005, diabetes affected 7% of the United States population and was the sixth leading cause of mortality.<sup>2</sup> This rate is expected to increase tremendously over the next half-century.

The American Diabetes Association has classified diabetes mellitus into two main classes, type 1 and type 2. Type 1 diabetes results from beta cell destruction and this usually results in a complete insulin deficiency in the body. This type is usually diagnosed in children and adolescents. Type 2, the most common form of diabetes, is a more progressive form of the disease that is typically diagnosed in adults and is characterized by an insulin secretory defect. Type 2 diabetes may account from 90-95% of all diagnosed cases of diabetes.<sup>3</sup> Complications of diabetes include the progressive damage, dysfunction and failure of various organs including the kidneys, nerves, heart, eyes and blood vessels.<sup>3</sup> Diabetes can also affect the limbs, particularly the feet. Cardiovascular disease, retinopathy, nephropathy, peripheral vascular disease and peripheral neuropathy are co-morbidities of diabetes. In addition to these serious complications, diabetes can often cause life-threatening events such as diabetic ketoacidosis and hypersomolar (nonketotic) coma resulting from biochemical imbalances. Infections, such as influenza or pneumoia are also a serious concern for patients with diabetes, as they are more likely to die as a result of infection than individuals who do not have diabetes.<sup>3</sup>

Diabetes has been associated with an increase in complications such as heart disease and stroke. In 2004, heart disease was noted on more than two-thirds of all diabetes-related death certificates in the elderly. Stroke was included in 16% of the diabetes-related death certificates in the same population, suggesting that diabetes impacts cardiovascular health over time. Mortality from heart disease is on average, three times greater in adults with diabetes, and the risk for stroke is 2 to 4 times higher in persons with diabetes. Hypertension is considered one of the largest comorbidities of diabetes, with nearly 75% of adults with diabetes reporting high blood pressure and/or use of prescription medications for hypertension in 2003-2004. Diabetes is the leading cause of other complications including blindness from diabetic retinopathy, kidney failure and resulting dialysis and non-traumatic limb amputation. Nerve damage occurs in 60-70% of the diabetes population.<sup>3</sup>

Many studies have shown that diabetes does disproportionately affect minority ethnic groups such as African Americans<sup>4</sup>, Hispanics<sup>5</sup> and Arab Americans<sup>6-9</sup> when compared to rates of diabetes in the majority of the population which is Caucasian, and while taking into account the overall rate of diabetes prevalence in the United States. In 2005, the American Diabetes Association reported that Native Americans or Alaska Natives had the highest prevalence of type 2 diabetes (18%). African Americans that were non-Hispanic had prevalence rates of 14.5%, followed by Hispanic/Latino Americans at 13.3%. Non-Hispanic whites had the lowest rate, just over 8%. While these estimates



have been adjusted for age differences in the population, there was no adjustment for individual variation within each population subgroup.

The causes of Type 2 diabetes and the differential impact it has on certain subgroups of the population are important to examine. While the known causes of diabetes such as diet and exercise play key roles, other less examined reasons such as culture and ethnicity may play an even greater role in determining environment and thus diet and exercise of the individual. While a genetic predisposition to diabetes may increase an individuals' chances of diagnosis, individual factors, such as diet and exercise, decreases this chance. Just as diabetes differentially affects the population, we also see a variation in adherence to diabetes medication within the diabetic population.

When the cost of treating diabetes is examined, the CDC, NIH and ADA report that the total overall costs of treated diagnosed diabetes in the United States was \$174 billion in 2007. Two thirds of this estimate is direct medical costs associated with providing care, and one third are indirect costs such as disability, loss of productivity and premature mortality. The average medical expenditure for a person with diagnosed diabetes is 2.3 times greater than in individuals without diabetes. Medical expenditures include services provided in ambulatory and institutional care settings and outpatient treatment costs including medications and durable medical equipment.

The literature on medication taking reports rates of non-adherence have been reported to range from over one-third of the population to as much as 93%

of the population<sup>10</sup>. The wide range is likely attributed to the ways in which adherence is measured. Adherence rates are also found to be generally lower for patients who suffer from chronic conditions, such as diabetes, than those who have acute episodes requiring treatment.<sup>11</sup> Medication non-adherence rates in adult diabetic patients on oral medications has been reported to be as high as 64%. Non-adherence rates for all chronic diseases is not much improved-around 57%, even for patients in clinical trials.<sup>12</sup> Overall adherence to diabetes medications is less than optimal in many different subgroups of patients: patients from India and Asian Indians<sup>13</sup>, American Indians/Native Americans<sup>14</sup>, African American<sup>15</sup>, Hispanics<sup>16,17</sup>, Chinese Americans<sup>18</sup>, and Arab Americans.<sup>17,19,20</sup>

Patient adherence to treatment recommendations has been shown to be related to many factors: disease related factors, patient socioeconomic status (SES), and other patient demographic variables, such as race, gender, health insurance status and social support.<sup>12</sup> Lower adherence rates in these populations can be a result of attitudes concerning health and illness, medication practices, beliefs in Western or non-Western treatments and other cultural and religious beliefs. Reasons for non-adherence can vary greatly. For some, nonadherence to medical treatment is sometimes seen as a rational choice patients make in an attempt to maintain personal identity, achieve health goals, and preserve health-related quality of life.<sup>21</sup> Research on adherence has typically focused on the barriers patients face in taking their medications. Common barriers to adherence are under the patient's control, such as forgetting to take the medication, distraction by other priorities, making the decision to purposefully

omit doses, not seeking information to make the best decision, and emotional factors that permit taking medication (i.e., depression), so that attention to them is a necessary and important step in improving adherence.<sup>11</sup>

### **Explanation of and the relationships between key study constructs**

The following section explains the constructs of illness identity, social identity, goal setting, support group participation and goal achievement and the relationships between them. Explanation of these constructs is conducted through selected published definitions and by demonstrating the applications of each within research studies that have been conducted in the literature. This section describes the constructs from a broad perspective that is not limited to the application of such constructs in the health care perspective.

#### **Illness identity**

Chronic illness is a “state of unwellness produced by disability or disease requiring medicosocial intervention over an extended interval and affecting many aspects of an individual’s life.”<sup>22</sup> A meta-analysis of the literature revealed that the themes of research on chronic illness have shifted from suffering, loss, biographic disruption and sick role to being courageous, maintaining hope, restructuring illness, reframing and reshaping the self, regaining control, redefining health, empowerment, transformation, and normality a decade later. There has also been a focus on the expertise of chronically ill patients in obtaining information about their illness and managing the illness and competence in health care decision-making.<sup>22</sup> Chronic illness can influence

social relationships-strengthening the relationships between family members in the care-giving process, creating new relationships with other chronically ill patients, and also changing the intensity of the relationship between the patient and the health care provider. It is important to understand the implications of chronic illness on identity.

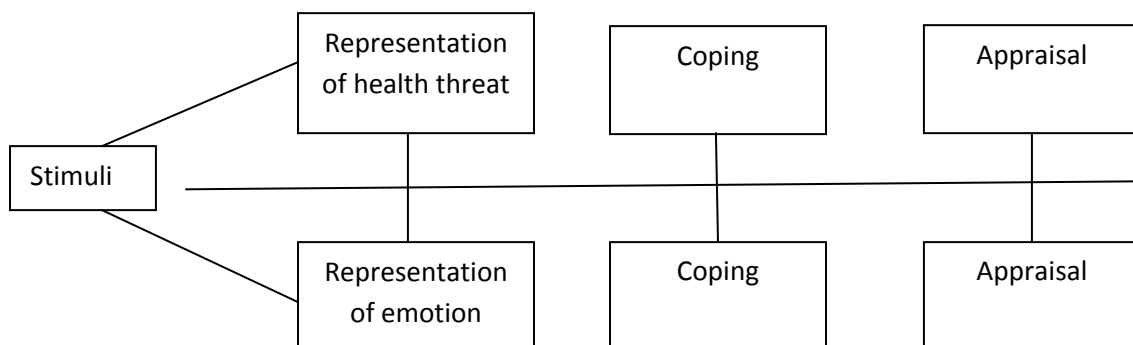
Illness is another means of identification. Social identity influences personal identity and is developed as the individual engages in various activities and personal networks such as work, recreation and family. Social representations of illness that are also developed through these activities and networks can impose upon the individual's illness beliefs.<sup>23</sup> Chronic illness creates identity problems that the individual must struggle with. Chronic illness upsets the balance between the body and the self, disrupting the sense that the body and self are whole. Daily life, self and identity are all impacted by chronic illness.<sup>24,25</sup> Former identities and future plans change and must be questioned and altered.<sup>26</sup> Long-term chronic conditions often result in changes in functioning and social roles, future plans and self-image.

### **Illness representations and perspectives**

Illness identity has been also called illness representations or illness perspectives. Illness representations are defined as an individual's beliefs about their illness based upon experiences, expectations and goals related to health and illness. Such representations can determine decisions to seek health care, coping behaviors used by the patient and compliance with medical advice.<sup>27</sup> The

individual's social network is also impacted by illness, and it has been shown that social networks influence health-related behaviors, as well as the patient's health beliefs and illness representations.<sup>27</sup> Leventhal and colleagues<sup>28</sup> have created an illness appraisal and coping model that has illness representations as the main component, taking into account the various role of social factors in constructing illness representations.<sup>27</sup> See Figure 2.1. The model suggests that health and illness behaviors result from threats to health and the coping processes that the individual uses to adapt to such threats. Illness representations, both cognitive and emotional are included in the model.

**Figure 2.1: Depiction of Leventhal's Illness Appraisal and Coping Model<sup>28</sup>**

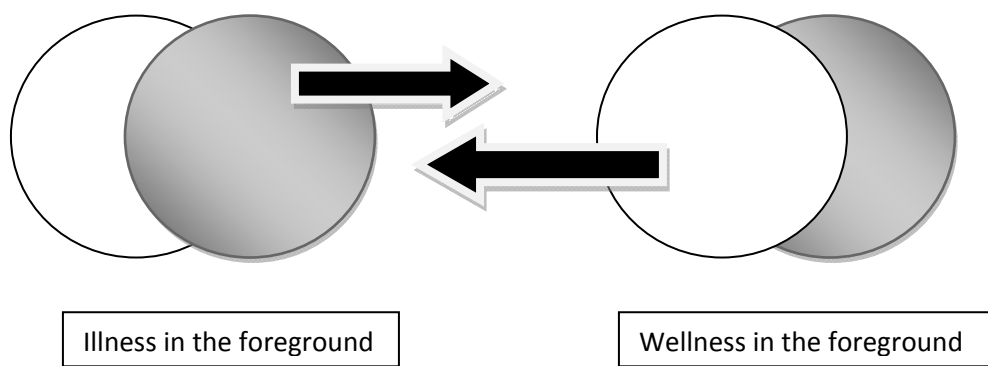


The emotional components of the illness representation illustrate the subjective experience of illness that can vary from one individual to the next. Emotions, such as anger, annoyance, depression and anxiety, can motivate the individual to engage in health related behaviors if the patient has an action plan, such as a proposed treatment regimen.<sup>28</sup> In the absence of an action plan, the emotion may totally overwhelm the patient and thwart health related behaviors. The model has been predictive of some aspects of adherence, because in the

model the patient is an active problem solver that can perceive the reality of the health threat and can deal with the threat emotionally. The representation of the illness, both cognitive and emotional, thus can guide self-management behaviors.

An illness perspective is conceptualized in terms of the beliefs, perceptions, expectations, attitudes and experiences pertaining to being an individual with a chronic illness. An example of a model of illness perspectives is the Shifting Perspectives Model of Chronic Illness<sup>29</sup> (see Figure 2.2), based upon the tenet that the experience of chronic illness is dynamic. Perspectives about the disease enable people to make sense of their experience.<sup>29</sup> Elements of illness and awareness are included in the model. Perspectives of illness and wellness are represented by overlapping circles, where at any given time one perspective will take precedence over the other. When wellness is in the forefront, the individual uses his chronic illness as an opportunity to create agreement between his self-identity and his illness identity, and changes his relationships with the environment and others in terms of his chronic illness.

**Figure 2.2: Depiction of The Shifting Perspectives Model of Chronic Illness<sup>29</sup>**



The patient can create agreement with these two identities by disclosing his illness and educating others about the illness and the health behaviors that the individual must not engage in. Incorporating changes in all aspects of the individual's public life-at work, at home and in private- will allow the patient to create agreement between identities and maintain wellness. Individuals that try to conceal their illness may engage in risky behaviors in public that can have detrimental health consequences. By reconciling the illness with the self, the self and not the effects of the chronic illness on the body are the source of identity. Agreement between the identities is one of the healthiest ways to manage chronic illness.

For the individual with chronic illness, it is the demands of the body that can influence how a person functions and interacts with others on a daily basis. The body makes up part of the physical identity, an identity that must be accounted for by the individual. The constraints of the body, as imposed by chronic illness are mostly social in nature, in a sense that society places those constraints on the individual, limiting interactions and abilities. The dual demands of bodily existence and social life must be reconciled for the chronically ill person.<sup>30</sup> Reconciling the illness and the body can be difficult when the symptoms cannot be seen or felt. If the individual conducts her daily activities and relationships as if nothing has changed, the seriousness of the illness can be lost. At times the medical perspective given by the doctor does not match the interpretation the patient has of the illness with respect to the condition of his

body, particularly if the individual is physically capable of demonstrating health despite diagnosis of illness.<sup>30</sup>

Chronic illness can threaten one's self-integrity and belies previous assumptions about the relation between body and self, disrupting the balance. Many individuals with chronic illness formulate future identities over present identities, envisioning themselves in the future and set goals related to that future identity, regardless if this identity is unattainable.<sup>26</sup> Bodily appearance and changes that occur as a result of chronic illness affects social identifications and self-definitions, therefore making it imperative to reconcile illness identity with social identity.

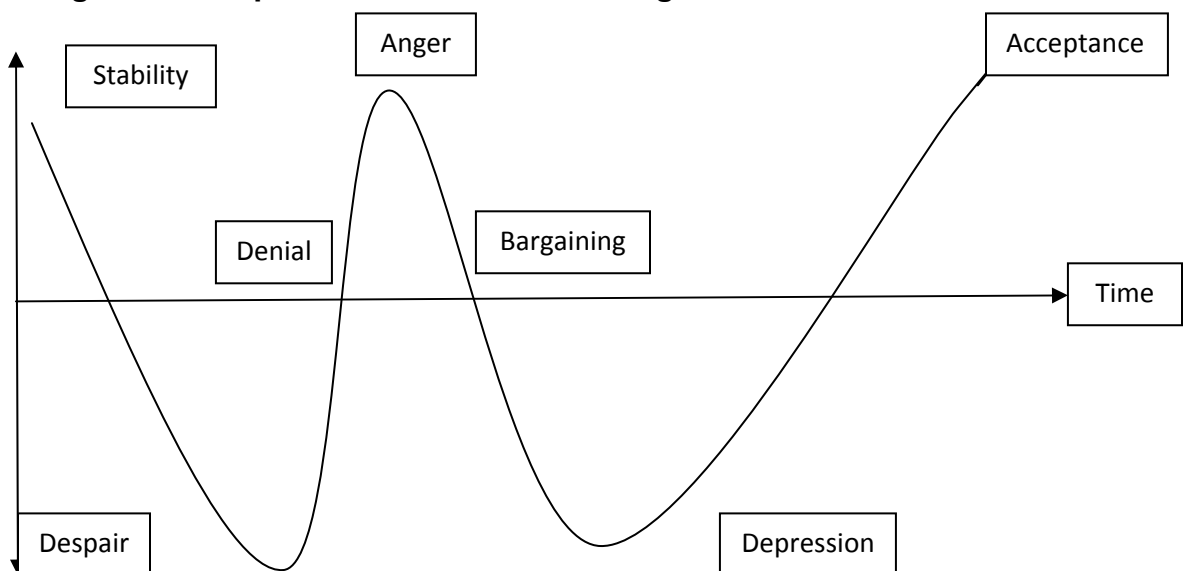
#### **Acceptance of diagnosis and the development of illness identity:**

Reconciling the two identities is a matter of incorporating the illness identity into the social identity. How the individual perceives his health and whether or not he accepts or rejects the diagnosis of illness determines how this process will occur. There are varying degrees of acceptance and denial that accompany the experience of diagnosis. Kubler-Ross<sup>31</sup> chronicled five stages of emotional adjustment that occurs in a model of grief. See Figure 2.3. Denial, anger, bargaining, depression and acceptance are the five stages. Denial is a conscious or unconscious refusal to accept facts and information as it relates to the situation concerned. It's a defense mechanism and perfectly natural. If the change demanded of the situation can be ignored, individuals can remain in denial for long periods of time. Anger can manifest itself in many ways. People



dealing with emotional upset can be angry with themselves, and/or with others, especially those close to them. Traditionally the bargaining stage finds individuals attempting to bargain with some higher power to negotiate a compromise. However, bargaining rarely provides a sustainable solution, especially if it's a matter of life or death. Depression is seen as preparatory grieving, and it is an acceptance with emotional attachment. Reality of the illness or death has registered. The final stage, acceptance, can indicate emotional detachment and objectivity of the patient towards the illness. Oftentimes, patients with illness can enter this stage before their family and friends, who must necessarily pass through their own individual stages of dealing with the illness.<sup>31</sup>

**Figure 2.3: Depiction of Kubler-Ross Stages of Grief Model<sup>31</sup>**



This model, used mostly in terminal patients, is also transferable to personal change and emotional upset resulting from factors other than death and dying, such as diagnosis with chronic illness. Individuals commonly move through what Kubler-Ross has identified as the five stages of adjustment as they

learn to accept a chronic illness. The emotional adjustment process from acceptance to denial is a transformational process. The individual with illness is constantly changing, growing and learning as a result of his/her illness. There are two themes that are discussed when examining transformation: the restructuring of the illness experience and the restructuring of the self.<sup>32</sup> The restructuring of the illness experience involves cognitively changing how the individual perceives the illness—from a threat to health to a challenge that can be met. This is a realistic reframing of the illness that incorporates the limitations of the illness with strategies aimed at adapting and regaining a sense of normalcy in one's life. Some individuals may opt to not normalize, as this may be seen as preventing the creation of a realistic identity with an illness. The first step in restructuring the illness experience is accepting oneself as an individual with chronic illness; the transformation process can be described as the process of regaining control.<sup>32</sup>

For most individuals, denial will gradually fade into acceptance. Denial is healthy so long as it serves as a protective function in the short term. Denial can result when a patient is conflicted or uncertain about how the illness will be incorporated into their life. Uncertainty is also the unorganized stage of illness, before a diagnosis is made that confirms a person's symptoms. However, uncertainty can remain after the diagnosis is made and relates to the meaning of the illness, the effectiveness of treatment, the impact of the illness on daily living, work, and social relationships. There are a variety of strategies to manage uncertainty, one of which can be denial.<sup>33</sup> The concept of denial was born from

the identification of defense mechanisms a la Freud. The individual tries to avoid situations that are threatening or that cause anxiety, and the individual can either refuse to acknowledge the situation or not acknowledge her feelings concerning the situation, often using defense mechanisms.<sup>34</sup> People can seek out other individuals with the illness, a network of others with knowledge and first-hand experience with the illness to help to come to terms with accepting the illness.<sup>33</sup> Irrespective of which stage the patient may be experiencing, support groups can be a beneficial network that can help the patient progress through the stages to acceptance, and to motivate the patient to self-manage the condition.

Traditionally research has focused on coping mechanisms and health outcomes from the process of acceptance, adaptation and the resultant positive outcomes. The results of such research also report that denial is significantly related to poorer illness management, higher distress and depression. Other research suggests that optimism, or positive illusions are helpful in coping with stress associated with chronic illness diagnoses.<sup>34</sup> In a literature review of acceptance and denial in response to chronic illness and disability, conducted by Telford and colleagues<sup>34</sup>, it was found that using a stage model in which the patients response to the illness or disability is characterized by denial or acceptance may result in internalization of the stage and its accompanying label. If the label or emotion associated with the stage is negative, incorporating such emotions may inhibit the restructuring of one's identity that enables them to self-manage and live with the illness or disability.

## **Social Identity**

Identities can define, locate, characterize, categorize, and differentiate the self from others, developing in stable roles and in emergent situations. Identities can also define the self in relation to others. Social identities are often derived from cultural meanings and community memberships, in groups and networks. Personal identities define a sense of location, differentiation, continuity, and direction by and in relation to the self. When identities are internalized, they become part of the self-concept, what Turner<sup>35</sup> defines as the relatively stable, coherent organization of characteristics, evaluations, and sentiments that a person holds about the self. An individual with diabetes can internalize the condition, and this internalization can alter the self-concept. The self-concept (also known as self identity) is made up of a personal identity component that results from various identities derived from social relationships.<sup>23</sup> For those from an individualistic culture, the self is personal identity and a social identity is the sum of the individual's group memberships, interpersonal relationships, social positions and statuses.<sup>36</sup>

Identity is formed by either self-categorization or identification. Social identity theory explains identity in relation to categories or groups and identity theory uses roles to define identity. Self-esteem and self-efficacy are processes that occur when identity is activated.<sup>37</sup> In Tajfel's previous work, he describes a process called inter-group approach that states individuals become familiar with one another through group identifications. Individuals perceive not only their own social identity, but also the identity of the group(s) to which they belong.<sup>38</sup>

Social identity theory states that the self-concept, or self-identity results from group membership, and the categorization process that an individual undergoes to define himself in terms of gender, race/ethnicity, class, etc.<sup>39</sup> This categorization process accentuates the differences between members of one category and those of another. Social identities describe and prescribe the beliefs, attitudes, and behaviors that minimize in-group differences and maximize inter-group differences, another way in which an individual will categorize himself.<sup>39-41</sup> Social identity theory examines when and why individuals identify with, and behave as part of, social groups. Studies using this theory observe inter-group relations, group processes such as self-categorization, and the social aspects of the self.<sup>39,40</sup>

Group membership allows for categorization, identification and comparison. Individuals seek to belong to a group to enhance self-esteem.<sup>42</sup> Groups are motivated to maintain in-group status and self-esteem by adopting acceptable behaviors.<sup>42</sup> The individual can have membership to many different such categories or groups. Each membership represents a social identity that describes and prescribes one's attributes as a member of that group and determines thoughts, attitudes and behaviors. Affiliation with the group can impact attitudes. Group members seek validation of attitudes and opinions from other group members. When one member finds that other members consistently share the same attitudes and opinions that he himself values, an internalization process occurs and intentions to express an attitude behaviorally will likely increase.<sup>43</sup> When social identity is salient, particularly for processes under self-

regulation for the individual, conduct is guided by what is supported in the group normative environment. While often used for comparative purposes, social identities are also evaluative, typically in the sense of shared consensus and self-evaluative consequences.<sup>42</sup>

How does social identity influence behavioral decisions? Social identity theory states that when social identity is salient in an individual, the individual will create a context-specific group norm from available, shared comparative information. This norm describes/prescribes beliefs, attitudes, feelings and behaviors that minimize in group differences.<sup>41</sup> According to the contingent consistency hypothesis, when a supportive normative environment exists, an attitude will be expressed behaviorally.<sup>44</sup> A supportive normative environment is one in which there are preconceived ideas that are favorable towards the behavior in question, and an environment in which the individual is supported by the group to engage in this behavior. An example of such an environment would be patient support groups.

Support groups have been created by health care professionals and professional practice associations to provide outreach to patients. Education, expertise and real life experiences are shared in such a setting. This group environment allows the individual to behave in congruence with his attitude while also receiving support and approval by the group and their environment. Behaviors that might be subject to approval by the group could include dietary habits, exercise and recreation, medication taking and alcohol and tobacco use.

The role of support groups and empirical evidence of support groups will be discussed later in the chapter.

As a result of the group approval process, social influence may occur when individuals in the group align their behavior to meet the expectations of others in the group whose values they regard as important.<sup>45</sup> And when social identity with the group is salient, the individual will create situational group norms from information about what is acceptable that is shared between group members. This information can be found through physical and virtual interaction with group members.

Group membership can cause individuals to think, feel and behave according to group norms.<sup>45</sup> Social identity is derived primarily from group membership, and many individuals strive to maintain a positive identity. For individuals with chronic illness this positive identity can be related to adhering to self-management behaviors that the group approves of or being a supportive group member.

### **The relationship between illness identity and social identity**

One of the primary aims of this study is to examine the relationship between social identity and illness identity in persons with type 2 diabetes. An individual's social identity is comprised of awareness of memberships and identifications with many different and sometimes overlapping groups and social categories. For example, an individual can identify with being a mother, an educator, a spouse, a feminist, a Democrat, an African American and a diabetic.

The salience of each identity influences the strength of one's attitudes toward and willingness to engage in particular behaviors. Illness, and identifying oneself as having an illness, can likewise influence an individual's attitudes and behaviors. Illness can also alter relationships one has as they relate to the aforementioned identities, in turn making the illness more salient to the individual. However, it is also important for individuals with chronic illness to be able to retain former identities, so as to not experience a loss of self, due to the salience of the illness. The self and the former identities may require adaptation to the illness; however, the illness identity should not be the prominent identity. A review of empirical studies suggest there are positive relationships between identity and illness<sup>21</sup>, and that individuals that identify with their illness are better able to cope, manage their illness, have more positive relationships with others and better health outcomes. To examine this aim, this study will measure the patient's acceptance of diagnosis of diabetes, and the degree of social identification as a person with diabetes.

The relationship between social identity and illness has often been reviewed qualitatively, using case studies, interviews and focus groups. In terms of how illness impacts social relationships, a qualitative study by Charmaz<sup>26</sup> of 57 chronically ill adults (ages 20-91), two-thirds of which were women, examined the effects of illness on the self concept and motivation. Subjects were recruited using convenience and snowball sampling procedures through referrals from practitioners, contacts from other interviewees and by visiting some in the hospital setting. Half of the subjects were classified as middle-class according to



education and occupation, approximately one quarter were upper middle class and one quarter were low-income or on welfare. In a series of interviews, Charmaz found a common theme of “loss of self” whereby the individual experiences disengagement from their social networks. Work, family relationships and future plans are disrupted. It is this disruption and sense of loss that influences motivation to self-manage diabetes and adhere to treatment recommendations.

In addition to a loss of social identity, individuals in the study expressed a strong desire to not be identified by their illness, in the sense that they are patients first and persons second. When self –management behaviors impact daily lifestyle and the individual feels his identity is more anchored as a patient than as a productive member of society, he might be less willing to engage in such behaviors.<sup>26</sup> Societal perceptions of illness may influence the patient’s response to the diagnosis and how he manages the condition. When the condition is less obvious, such in the case of diabetes, the meanings the patient gives to the illness can significantly influence the identity re-structuring process, and this can vary from one person to the next. One person may view diabetes as stigmatizing, isolating him from his peers in the sense that now he has to plan and execute self-management behaviors. Another person may embrace her diabetes as a reason for a healthier lifestyle and now a part of her life. Several patients interviewed stated that the diagnosis of diabetes encouraged them to change habits and was the push needed to implement such change.

To further investigate the findings of the above study, Charmaz conducted another qualitative study<sup>24</sup> with the same aims, examining patients with heart and circulatory disease, cancer, emphysema, diabetes, chronic fatigue syndrome, rheumatoid and collagen diseases and other auto immune diseases. Themes that were extracted from the transcribed interviews included: experiencing an altered body, coping with changes in bodily appearance, bodily changes and changing identity goals, identity trade-offs, and surrendering to the sick body.<sup>24</sup> In this study, the patients emphasized the effects of illness on the physical body. For illnesses that are more debilitating such as arthritis and multiple sclerosis, changes in bodily appearance can heighten the identity issues that individuals face, primarily because the illness is outwardly visible to others and the physical limitations imposed upon the patient may have a greater influence on the ability to maintain work and family expectations. For other conditions such as diabetes and hypertension, where symptoms of the illness might not be outwardly recognizable, the patient might experience different issues with reconciling an identity of a person diagnosed with chronic illness with a body that appears to others as “healthy”.

People living with illness may choose to ignore, minimize, reconcile or embrace the illness. If the individual can control the illness or its symptoms (such as diabetes), and the illness has little influence over his or her life, he or she may choose to ignore or minimize the illness. These processes may also occur when there are competing demands such as a job or relationship that takes precedence over the illness, as witnessed in the studies by Radley and Fife

discussed in the previous section. When ignoring or minimizing the illness, the balance between the body and self that existed prior to the illness is preserved in a sense. These individuals do not accept the illness, nor let it define whom they are, refusing to accept how others perceive they should behave as a person with such a condition. When embracing the illness, the individual seeks refuge in the condition. All of these processes can be experienced at any given time during the lifetime of the illness. Although, some individuals never adapt to the illness, refusing to admit that they have suffered any losses, while others may only adapt after experiencing losses related to their illness. Some individuals pursue contradictory identities, wanting to be a passive patient one day and fully recovered and working the next, without realizing that the latter identity requires the patient to be actively engaging in self-care behaviors.<sup>24</sup> Contradictory identities have serious implications for medication adherence, and many studies<sup>11,46</sup> have demonstrated that patients do make alterations to their treatment regimens, skipping doses or splitting tablets when not advised to do so. However, many studies examine the economic reasons patients behave in such a way, not focusing on the more cognitive and emotional aspects of identity that may influence self-care behaviors.<sup>45,47,48</sup>

Individuals with chronic illness may make identity trade-offs, opting for one identity over the other.<sup>24</sup> This can be dependent on the situation and the demands of the situation. For instance, a chronically ill patient might want to appear healthy in order to be hired for employment, choosing her former “healthy” identity over her illness identity. The same individual may opt to have

her illness identity more salient when meeting with her physician. The adaptive process of adjusting to illness is a rationalized response to the circumstances of the illness, ongoing in the context of social relationships and situations.<sup>30</sup> The above trade-offs might occur automatically or in relation to the severity of the illness at that given time.

### **Accepting chronic illness: implications for social identity**

Illness and social identity has been specifically studied in patients with type 2 diabetes. One study aimed to characterize the effects of illness on social identity, examined 30 adult patients with diabetes.<sup>49</sup> (Kelleher 1988) The study found patients that had difficulty accepting their illness were unable to manage their daily treatment regimen and thus had poorer health outcomes. People who accept their diabetes and successfully manage their condition were found to have many positive relationships that reinforce a positive identity. These findings suggest that certain patients have better health outcomes because they understand and accept the illness and the necessity of treatment in managing their condition. While accepting a diagnosis and understanding the effects of illness and medication on the body are not one in the same, knowledge is one factor that should improve acceptance in patients. Patients can increase diabetes-specific knowledge while also receiving support and acceptance from other members in diabetes support groups. The study also found a link between acceptance and social relationships, which provides evidence that acceptance allows the individual to incorporate the illness into his social identity. This

strengthens previous relationships, and perhaps encourages the patient to seek new relationships with other patients.

In a case study done by Tilden<sup>23</sup>, qualitative methods were used to extract major themes emerging during the course of psychotherapy with an adult with type 1 diabetes and to relate these to poor adherence. Tilden<sup>23</sup> found an embedded theme that was related to the desire to have the self recognized and not the disease, similar to the findings of Charmaz<sup>26</sup>. The challenge of this particular study was to identify the individual's defense mechanisms to combat the illness, identify underlying affect and facilitate the integration of a "diabetic identity". The socially constructed diabetic identity was found to change by cognitive awareness and positive action that interrupted negative patterns of communication between the patient and provider about the illness. Shifting the representation of illness to allow the self to be more prominent can allow one to be more assertive in caring for the illness and to take responsibility for social relationships that can influence the acceptance and management of the condition. The main finding was that poor adherence resulted from a rejection of a "diabetic identity". For the patient in the study, the socially constructed diabetic identity changed through cognitive recognition and positive action, i.e. changing attitudes toward the illness as being a battle between herself and her providers to giving them a second chance and regaining control of her condition.<sup>23</sup> These findings have implications for the patient-provider relationship in that by accepting the illness, patients are more able to communicate and share decision-making with their provider. Attitude change and taking responsibility for social

relationships can occur through the support and motivation mechanism of support groups.

The aforementioned study illustrates that illness Identity can influence the social relationships one has that are new, such as the relationships with providers and other patients that result from the illness. However, social relationships that existed prior to the diagnosis can also be affected. The DAWN (Diabetes Attitudes, Wishes and Needs) study was an international study that examined self-management approaches to care and the relationships between people with diabetes and their family, friends and caregivers. Over 5,000 patients with diabetes and 3,000 health care professionals in 13 countries participated in this study that addressed the psychosocial needs of patients. The study included adult patients with established identities that are diagnosed with diabetes (both type 1 and 2). Both types were included and it is important to note that each type might experience the illness differently and with different influences on identity. Type 1 patients, typically diagnosed in adolescents, might have more difficulty developing an identity, or have differential identity formation processes, because it is thought that self-identity is truly developed at adolescence.<sup>23</sup> (Tilden 2005) Adults diagnosed with a chronic condition will likely already have a self and social identity intact, and thus will need to make changes and adapt their identities in the context of illness.

The aim of the study was to understand patient perceptions of diabetes and barriers to effective self-care. The attitudes and responsibilities of policy makers and healthcare providers were also assessed. Patients were interviewed in

person or over the phone. Themes that were found included emotional distress with the illness, execution of familial responsibilities, concerns with weight and disease progression, negative effects of unwanted support, and fear of hypoglycemic events. One interesting finding was the notion of a “diminished self” related to unwanted support and pressure by others that make the patient feel like a “criminal”. At times, individuals felt that society acted like “diabetes police” and this had negative effect on well-being and self-care behaviors. Diabetes can be detrimental to social relationships, making it important to incorporate psychosocial care into overall diabetes management.<sup>50</sup> (Snoek 2002)

It may also be helpful for patients with diabetes to seek support and advice from other patients to cope with unwanted support. It is imperative that patients receive the right type of support to self-manage their condition. The results also demonstrated that individuals with diabetes that do not have a community of support are more likely to be ineffective at managing their illness. Diabetes self-care entails many tasks and responsibilities for patients, their caregivers and their families and friends. Not having support from caregivers and others can result in ineffective management and poor health and well-being. A community of support can also be found among other patients with the same chronic illness and these patients, particularly those who have managed the condition for some time, can offer advice and recommendations for newer patients to help them cope and manage their condition.<sup>50</sup>

One study interviewed 38 persons at various stages of cancer recruited from the oncology and radiation therapy clinics in a community based cancer

center.<sup>51</sup> Interviews with patients found that in coping with the illness, it is imperative that the individual continue to strive for goals that existed before the diagnosis of illness, redefining them as necessary to be realistic. This can occur through behavior modification and lifestyle changes. It was also found that illness was a threat to one's self esteem, which can lessen one's social status and standing and impact personal relationships. These threats can be remedied by increasing social support (i.e. joining a support group) and maintaining health goals (i.e. low HbA1c values and being adherent to medications) to help preserve former identities.

### **Illness and its impact on social relationships with others**

A study of 48 adult patients with asthma and 47 general practitioners was conducted to examine the meaning of health for both groups and to determine if patients with asthma view their health in ways to preserve self-esteem and thus keep their social identity intact. Telephone interviews revealed that there were significant differences between providers and patient's definitions of health.<sup>52</sup> Providers view health as an absence of disease or illness, while the patients viewed health in terms of self-esteem and "being able" and physical well-being. It was also found that individuals with chronic illness may psychologically distance themselves from being labeled a member of a group of people with an illness, or they might compare themselves with others worse off to preserve self-esteem.<sup>52</sup> For these reasons, individuals may be less likely to seek out support groups or share with another person with the same chronic condition. However it is unclear why this distancing might occur because the authors did not measure



respondent's social identity and therefore could not adequately capture reasons for such behavior.

Additionally, research examining provider-patient communication sometimes focuses on individual's personal and social identities. Personal and social identities are created through interaction with others, and diagnosis of a chronic illness can influence social constructions of reality and relationships with others.<sup>38</sup> Three levels of identity have been used to examine inter-group approaches for patients with cancer. The first identity, primary identity, is related to large social groups such as race/ethnicity, sex, age, etc. The secondary identity focuses on health related behaviors, such as smoker, jogger, etc. The third identity is the identity involving being diagnosed with an illness. For the primary identity, stereotypes of social groups can influence diagnosis and treatment in the sense that providers utilize cognitive schemas and heuristics to care for their patients. For secondary identities, if the individual has a sense of identification with others who execute healthy behaviors, the individual is more likely to maintain healthy behaviors. For the tertiary identity, the individual has to identify as being ill, and this in turn results in information and support seeking behaviors and ultimately adherence. As individuals identify with other patients in support groups, the likelihood that they will engage in group practices related to health care behaviors increases.

In addition to support from other patients with chronic conditions, family and friends are often the main caregivers for chronically ill patients, making it important to understand how they might conceptualize the illness. In interviews

with patients with chronic fatigue syndrome (n=49) and Addison's disease (n=52) and their spouses, concordance with the illness identity and the cause of the illness was found between the couples, but no agreement concerning time-line, cure and consequence. Illness identity beliefs are related to symptom assessment and the ability to connect the symptom with the illness. Time-line signifies an idea about the likely duration of the illness that the patient has, and can signify a belief that the illness is chronic in nature. Cure is related to the ability of the individual to control or "cure" the illness. Consequences are beliefs about the outcomes of the illness and perceptions of the seriousness of the consequences. Adherence may also be a result of perceived symptomatic benefit in these patients.<sup>53</sup> The lack of agreement between spouses did not negatively impact coping behaviors, but it did influence adaptive outcome. When dissimilarity in representations of Addison's disease was found to be great between the spouses (i.e. the spouse maximizes the number of symptoms, the duration of the illness and the consequences or vice versa) the patient was found to have a higher level physical functioning, social functioning and psychological adjustment, than those spouses who agreed on the illness representation.<sup>54</sup> This dissimilarity can be positive, especially if it helps "balance" the perspective of the illness so that if the patient is exaggerating the symptoms of illness, the spouse can minimize them and encourage the patient to engage in social and physical activities, and thus maintain previous identities through adaptation.

Another study examined 42 men with coronary heart disease requiring graft surgery. The patients and their spouses were interviewed to determine the

adjustment to the diagnosis and the prospect of surgery and the response to surgery. A measure of adjustment to illness was developed by the investigators on the basis of Herzlich's analysis of people's representations of illness behavior. It was found that when the individual dominates the illness, normal life is maximized while symptoms are minimized. Another finding was that the illness can also be experienced such that all aspects of healthy life are destroyed. Patients then either embrace the illness as a restriction on their existence, or they alter activities to accommodate the demands of the body. It was found that responses to illness that result in positive outcomes include maintaining family role structure, having role flexibility and making changes to accommodate the illness.

In a related paper, Radley supports these findings by stating that chronically ill individuals do not adjust to physical symptoms within the context of shared social demands. Illness amplifies an individual's position within society, making it essential to adjust with societal expectations. Historically societal expectations were more gender-based; however, the gender line demarcating social roles and obligations has become more blurred, allowing patients and their spouses to exchange traditional roles and behaviors to accommodate the illness and treatment of the illness if necessary. However, socioeconomic status (SES) may influence the impact that illness has on role obligations, such that individuals with lower SES might not have as greater flexibility as those with higher SES with respect to exchanging societal roles and obligations. For example, the husband that is diagnosed with a chronic illness but who is also the highest wage earner in

the home might not be able to take time off from work related to his illness. It has been found that individuals of lower SES have greater indifference to symptoms, which can be interpreted to suggest that individuals with greater SES monitor symptoms and illness more, however, it might also mean that symptoms are ignored in order to execute other societal roles and obligations such as work.<sup>30</sup>

### **Support Groups**

Social support has oft been studied for its role in health care. Its influence on self-management, adherence to medical recommendations, lifestyle changes and outcomes of care has been studied.<sup>21,55</sup> Social support and the relationships one has within their social network have been proposed to improve health behaviors, decrease negative affect and improve immune system functioning.<sup>56</sup> (Barrera 2002) Different from one's support network, which merely indicates the number and type of social linkages one has, social support is the quality of the relationship, the content or emotion about the influence the relationship has on how the individual feels and acts. Social support can include interactions between family, friends, peers, neighbors, colleagues, and fellow patients that are either physical or aided through the use of technology.<sup>55</sup> These interactions can also influence one's social identity and it is the same interactions that can lend support to the patient in identifying with his illness. For the purposes of this study, the role of social support groups for diabetes in the identity and goal behavior process will be examined.

Before the main study relationships are discussed, it is necessary to illustrate the reasons why patients would choose to become a member of a support group, particularly when many patients already receive social support from their family and friends. However, the patient's current support network may not provide sufficient support because this support network lacks experience with stressful life events, or family and friends are uncomfortable dealing with the stress of illness, or have difficulty processing the impact of the illness on their own life. Family and friends with an illness may be consumed with their own health and unable to provide support to a family member or friend with an illness.<sup>57</sup> Additionally, individuals that have problematic relationships with family and friends might gain more benefits from a peer-support group.<sup>57</sup> Support groups can also be a source of supportive information that the individual can share with his family and friends.<sup>58</sup> Support groups for caregivers and family and friends can also be found online.

There are many benefits to patients who belong to social support groups, such as overall improved quality of life, decision making and mortality. Such groups can also offer a more cooperative means to incorporate the cultural and social needs of the patient than the clinical encounter with health care providers, and this can be very empowering.<sup>59</sup> Besides empowering patients, these low-cost interventions can result in other positive psychological benefits for the patients, such as improved self-esteem, confidence and optimism. Social support itself has been found to be significantly associated with physiological benefits as well. More specifically, diabetes patients that receive support have improved blood

glucose control, and the reasons for this are three-fold: support can provide diabetes-specific information, support provides an emotional buffer against stress and finally, support provides coping and adaptive strategies to manage the illness.<sup>55,57</sup> Illness coping and adaptive strategies are guided by how the individual cognitively perceives the illness, how he or she represents his or herself in the context of the illness and how this illness is socially expressed.<sup>60,61</sup> This “social expression” of illness is often the formation of new relationships with other chronically ill patients. These relationships can be formed within social networks available for patients of chronic illness. Support groups can act as buffers, ameliorating the effects of ill health.<sup>62</sup>

The benefits of support groups can be broken down to cognitive, evaluative and affective (emotional) components. The cognitive component is related to the education and informational processes that the support group provides. The needs of the patient that are related to knowledge include disease-specific information, treatment side-effects, treatment plans, professional contacts and supportive information for family and friends.<sup>58</sup> Typically, patients with diabetes undergo an education process that involves a certified diabetes educator or health care provider teaching the patient one-on-one or in groups. These educational groups differ from support groups because they often lack a focus on experiential knowledge.<sup>57</sup>

Patients often use support groups when they find themselves in novel stressful situations that cause uncertainty about feelings, thoughts and behaviors.<sup>57</sup> Subjective uncertainty results when contextual factors influence an

individual's cognitions, feelings and behaviors, bringing uncertainty to the self. In order to become more certain, individuals communicate to reduce uncertainty, seeking information from others and the environment.<sup>63</sup> Information that is sought from support groups can be related to the diagnosis and prognosis of the illness, understanding the disease and its treatments, and learning management strategies. Information can be collected by various means and media, often resulting in mixed biomedical accuracy, but also results in patient independence and means to accomplish treatment.<sup>33</sup> Many support groups enlist health care professionals, either diabetes specialists or certified diabetes educators, to help moderate support groups. Self help groups present a particular view of the illness experience and many different lay and professional perspectives on the illness are conceptualized.<sup>33</sup> The types of information that are presented and the means by which certain individuals share such information make support groups a valuable source of information.

Self-help and support groups have been identified as an important avenue of information, particularly at diagnosis. A qualitative secondary analysis of a primary study of expertise in self-care decision making in patients with type 2 diabetes (n=7), HIV/AIDs patients (n=7) and Multiple Sclerosis (n=7) was conducted by Thorne.<sup>64</sup> Participants were nominated by primary care physicians and had to have several years' worth of experience in self-care decision making for diabetes. Individual interviews and follow-up think aloud sessions whereby the individual recorded all self-care decisions on audiotape for one week periods. Additional interviews were conducted to further explore reasoning for the basis of

certain decisions. This study found that all participants, regardless of type of illness, felt that self-care decisions were made with awareness of responsibilities to themselves and others, as well as the credible experiences of peers in similar situations.<sup>64</sup> These findings suggest that illness influences the social obligations and relationships one has with others and that previous responsibilities might influence the execution of self-care behaviors. The idea that peer accounts or experiences influence self-care decisions is one of the hypotheses of this proposed research. For the subjects of Thorne's study, the idea of being in control included a restructuring of the illness conception, one's relationships with others and the relationship with the "diseased" body. Self-care goals were set in response to bodily cues when the individual assumed control of the condition. This process also resulted in the development of collaborative and supportive networks.<sup>64</sup> Many patients felt that self-care treatment decisions should be participatory; however, patients with diabetes felt that physicians were unsympathetic and dispensed impractical, textbook medical advice that was not applicable to "real-life" diabetes. The advice from specialist practitioners was more readily accepted.<sup>64</sup>

Specialist practitioners and other individuals with the illness were valued as sources of information. Participants found that while support groups primarily served in an educational capacity, many members continued participation in a more social function. However, individuals with diabetes rarely felt the need for the social aspect of the support group after the initial information was acquired, and avoided social contact with others in which the disease was the focus.



Those with multiple sclerosis sought such groups to elicit empathy from others regarding the challenges of living with the limitations of the disease.<sup>64</sup> It is not clear if these results are generalizable to the entire population with diabetes or multiple sclerosis, or the role that acceptance of the illness plays in the decision to seek support and continue membership in support groups.

The next component, the evaluative component, refers to how the individual evaluates their illness in a group context. The role of support groups in the identity formation process is in fostering the social comparison that occurs during the self-categorization process. This is the motivational mechanism of Social identity theory. Social categorizations are based upon social comparisons.<sup>63</sup> Individuals seek to maintain a sense of normalcy in their lives and that in times of uncertainty (i.e. illness) individuals seek out others and their opinions to dictate behavior.<sup>65</sup> Social comparison principles state that in times of distress, individuals will compare themselves with others to evaluate their feelings and abilities.<sup>66</sup> Social comparison processes tend to occur between individuals that are similar to one another in some regard.<sup>67</sup> This comparison can be upwards and the individual will compare themselves with someone that they perceive as “better off” to initiate self-improvement behaviors. Downward comparisons are often done to enhance self-esteem by comparing oneself to someone that is perceived as “worse off”.<sup>57</sup> Patients can reinforce self-esteem by comparing themselves to other patients not successfully coping with the illness.<sup>36</sup> This can also negatively impact the comparator by inducing feelings of anxiety

over their own potential for decline. The social comparison process that occurs between support group members has not been thoroughly assessed.<sup>57</sup>

The similarity attraction paradigm is founded on the notion that individuals are attracted to others with similar ability, attitudes, values and experiences in order to evaluate themselves and validate their own attitudes and beliefs, thus making behavior more predictable.<sup>68</sup> Individuals may differ in their chronic condition orientation, as described in Paterson's model of shifting chronic illness perspectives. Some patients will focus more on health (wellness) than illness. Paterson asserts that self-help groups can cause the individual to focus on the illness, by participation in-group discussion. Messages from other group members that are not in accord with the individual's wellness perspective will cause a shift from the wellness perspective to the illness perspective. Individuals with chronic illness may selectively choose whom they interact with by sharing their experiences with individuals that preserve their preferred (wellness) perspective.<sup>29</sup>

As such, support groups can be a source of positive identity information, motivating one to engage in behaviors. This may occur because an individual wishes to improve status (i.e. become known as a "compliant patient"). Or individuals believe they are a member of a high status group (patients in control of their condition) or are a high-status member of the group (the go-to person for advice, the person with the most experience, etc.). To maintain this identity they are cooperative. The success of the group may be something they value.<sup>69</sup> Even

when the status of the group cannot be changed, a member of that group can still behave in such a way to increase his or her own feelings of self-esteem.<sup>69</sup>

Finally, an individual's relationship with a group is often related to favorable supportive attitudes and emotions. An individual's feelings about themselves are based on their sense of self (personal identity) and their feelings about the status of the groups to which they belong (social identity).<sup>69</sup> For individuals with chronic illness having a shared illness identity with another individual may be helpful, decreasing emotions of isolation, despair, depression and stigmatization that may result from diagnosis of illness. A member of a socially stigmatized group, such as chronic illness support groups, may behave in accordance with the group (i.e. take medications) because in doing so, this increases hopefulness, confidence and well being which in turn facilitate the maintenance of a positive social identity. The support group can influence attitudes and emotions one has toward their illness, about them and about others with the illness.

Attitudes have oft been linked with intentions in many health behavior theories, such as the Theory of reasoned action and the Theory of planned behavior. Social identity theory states that it is one's identity that describes and prescribes the beliefs, attitudes, and behaviors that minimize in-group differences and maximize inter-group differences.<sup>39</sup> Shared social identity, and attitudes related to this identity, may increase motivation and intentions to set goals to manage diabetes.

Managing the illness allows patients to live as “normally as possible”, redefining relationships with others (social identity) in the context of the illness. Participants in one study noted that the decision to assume control of their illness resulted in changes in lifestyle, heightened vigilance for symptoms and membership to collaborative and supportive networks.

Changes in lifestyle, education and self-care are all required of patients with diabetes, and the processes have been historically talked about in the clinical setting, or face-to-face in education programs or support groups. Technology has allowed the extension of interaction to the virtual community, an effective means of communicating about chronic illness management. Many access the internet for health information, preferring interactive exchanges of health information over static educational information.<sup>70</sup> Online support groups have a greater potential of reaching more patients of chronic illness than traditional face-to-face support groups would. For online groups, it has been suggested that for every one active reader, there are 20 passive readers. This increases the potential influence of the internet.<sup>62</sup>

### **Online Support Groups**

The use of the internet as a source of health information has oft been studied, with the users being characterized and the types of usage documented.<sup>71-74</sup> The Pew Internet & American Life Project<sup>74</sup> (n=2,928; 2006) found that in 2004, about 51% of people living with a chronic illness go online, compared with 74% of those who do not report a chronic illness or disability. This percentage has jumped from 35% in the same survey conducted in 2002.

Sixteen percent (n=43) of these patients with a chronic condition (n=268) use an online social networking site, which can include an online support group for a chronic condition. In another survey of 1980 persons, it was found that 34 to 53% of patients with chronic conditions use the internet for health information.<sup>71</sup> Thirty four percent of the study population that used the internet had cardiac-related chronic conditions and 53% classified as having diabetes. Overall, it was found that 13% of the entire study population used the internet to communicate with other patients, similar to the types of interactions one would find in an online support group.

It is unclear how many individuals use online support groups beyond what each site may display as “members” or site “activity”. For example, some of the larger groups include dLife® ([www.dlife.com/diabetes-forum/](http://www.dlife.com/diabetes-forum/)) that has over 21 thousand members; Diabetes Talkfest® ([diabetestalkfest.ning.com/](http://diabetestalkfest.ning.com/)) has almost 900 members; Diabetes Daily® has approximately 20,000 members; Tu Diabetes® ([tudiabetes.com](http://tudiabetes.com)) boasts 6,666 members. Historically, online social support communities were formed on dial-up bulletin boards in the early 1990’s. The world-wide web then incorporated discussion boards and chat rooms to allow communication in real-time. The online social support theory describes the process of support and information exchange that is characterized by interpersonal relationships between anonymous persons. Online social support is “the cognitive, perceptual and transactional process of initiating, participating in, and developing electronic interactions or means of electronic interactions to

seek beneficial outcomes in health care status, perceived health, or psychosocial processing ability.”<sup>75</sup>

Online discussion groups allow individuals with chronic health conditions to share their experiences with others seek information and advice and provide and receive emotional and practical support. Such online groups have been referred to as computer-mediated social support (CMSS). CMSS has challenged the social relationship between the patient and the provider. This self-help movement offers patients another source of support and information that previously was only found in the clinical setting, albeit sometimes lacking. In such groups, the expert recommendations of the provider are compared to the legitimate experiences of fellow patients. Expert medical advice is being coupled with lay knowledge for patients making decisions regarding management of chronic conditions. Medical advice can be checked, verified and discussed in virtual forums.<sup>62</sup> Experts moderate the accuracy, content and appropriateness of the interaction in online support groups and develop tailored patient-specific information for the patient.<sup>70</sup>

A benefit of online groups is that the availability and diversity of online support groups surpasses those of physical support groups. There are no geographical or transportation barriers to online support groups, which is of importance for patients with debilitating conditions, speech problems or hearing difficulties. Patients on intense medication regimens that experience major side effects can more easily participate in virtual support groups. Even the illness itself can prohibit the individual from participating in local support groups.

Sociodemographic variables such as gender, race/ethnicity, age, income and social status are not the focus of such groups, communication is. This allows relationships to be initiated on the basis of shared interests and not shared social status.<sup>76</sup> Even individuals of lower SES can participate through their local public library, which offers internet access to all members of the community. Such groups have the ability to reach patient populations that have not been reached or have been difficult to reach.<sup>59</sup> The group is a more diverse heterogeneous patient population, which results in a more diverse exchange of information and viewpoints, and perhaps increased exchange of information that may not be exchanged in more intimate relationships.<sup>76</sup>

To determine who actually uses such groups, some researchers have investigated the demographics of such programs. The Diabetes Network (referred to as D-Net) is an online diabetes support program that was used in an intervention of peer social support and personalized dietary services. Glasgow and colleagues first conducted a study to see who would use the program if given free unlimited access for one year.<sup>77</sup> From 650 eligible patients of 16 primary care physicians, 238 were deemed ineligible (due to lack of access, too ill, or not type 2) and of the remaining 265, 160 were eligible and interested in participating. There were small but significant differences between participators and decliners, with the participators being slightly younger and more newly diagnosed. The reasons most declined were related to the time required, not wanting to participate in research or having to use a computer.<sup>78</sup> There were no differences between the two groups with respect to owning or familiarity with

computers. In a follow-up to the intervention, a subset of a population of 320 type 2 patients were randomized to a peer support condition that allowed them to interact with each other in a peer-directed, but professionally moderated online forum, both in real time and in linked posts.<sup>79</sup> In addition, this group received electronic newsletters about support throughout the study. All participants, regardless of group assignment, set initial dietary goals that were reassessed at 3 and 6 months using the interactive online tool. There was no usual care group, and other groups included an “information only” group that had computer access to diabetes articles, but not support or coaching; a tailored self-management group had a professional coach that provided ongoing dietary advice and education.

The results of the D-Net study demonstrated that over time, participant’s use of the website declined and because the sample size was limited in the peer support group, there was limited activity on the site at any given time and this may have contributed to the decline in participation over time. Although not significant, there were positive effects of tailored self-management and peer support on a reduction in HbA1c from baseline and an increase in perceived support on the diabetes support scale for those in the peer support group.<sup>79</sup> These findings suggest that implementing such an intervention or creating a site may not have the far-reaching effects that established peer support groups may have on patients with type 2 diabetes. The lack of consistent interaction with either a peer or a coach may limit the effect of the interaction and a larger support group may demonstrate different results. It is also unclear from the



published results what the exchanges between peers in the peer support group consisted of and how these interactions might or might not have had an effect over and above the electronic newsletters these participants also received.

Content analysis of the interactions that take place in the form of messages, posts to forums and chat rooms can be helpful in understanding the interactions between virtual community members.<sup>80</sup> Studies examining the benefits of virtual support groups found that the majority of posts on such community boards include emotional support (40%), information seeking (31.7%), self-esteem (18.6%), networking (7.1%) and tangible assistance (2.7%).<sup>81</sup> Studies that examine the content of interactions that occur in virtual support groups have found that these interactions are very similar to those made in face-to-face interactions between members of physical support groups.<sup>56</sup>

There are daily decisional processes that the patient must attend to regarding medication, diet, rest and activity, symptom monitoring, and deciding when and how to seek help. In the absence of definite symptoms, these decisions can be even more perplexing for the patient.<sup>64</sup> In order to make these decisions, the patient must go through many processes. One such process is self-assessment. If an individual is uncertain about his or her ability to successfully complete a task, he or she may not perform the task. There is a preference to engage in tasks that are maximally diagnostic of individual ability to complete the task. In addition, individuals may be unwilling to seek potentially threatening information about their illness; however they may be more apt to do this when encountering a life change or when making life-altering decisions.<sup>82</sup>

This process of seeking information may be less threatening when done online, and the current trend in health care decision-making is consulting others for information relating to the illness before incorporating health care provider's recommendations.<sup>83</sup> It is imperative to assess the individual's perceptions as they relate to his or her identity and illness when examining behavior and adaptation to illness in a clinical setting. Taking these meanings into account will enhance the provision of holistic care. Approaches to care that foster a positive identity are important.<sup>51</sup>

A meta-analysis of 38 studies examined the effectiveness of virtual support groups.<sup>80</sup> Twenty of these studies were randomized controlled trials, three were meta-analyses, three non-randomized studies, one cohort study and eleven before-and-after studies. Of these 38, only six studies could be characterized as true peer-to-peer interventions. The other studies included interventions that included some virtual support group component in addition to other components. This might make the evaluation of the benefits of peer support difficult, as positive results can be attributed to a number of different components of the intervention. The six studies were all classified as before-and-after studies and included chat rooms, web-based discussion forums, a voice bulletin board system and an email correspondence list. Only one of these studies had no moderation from a health care professional, so the other five were not technically pure "peer-to-peer" interventions. The quality of all 38 studies included were questionable, as some randomized controlled trials did not adequately describe their randomization process or did not truly randomize

subjects, and most results were self-report. As such, this meta-analysis failed to show significant benefits of online support (both peer and other). Any statistically significant findings were not adequately described as clinically meaningful group differences. Many studies included were exploratory and utilized many different instruments to compare many different attributes, which minimized the value of positive results. Low sample sizes result in studies that are not adequately powered to generalize findings.

Five of the studies evaluated communities of patients with diabetes. Of these, four evaluated effectiveness of the group by HbA1c levels of members. One of the studies showed a significant improvement. These studies include the one conducted by Glasgow that was previously discussed. Two of the studies were dissertations and complete information could not be found regarding the study details. One of the studies, conducted by Barrerra, gave 160 patients with type 2 diabetes access to computers and internet access to examine if there were differences in perceptions of support between groups that received information and those that received support.<sup>56</sup> The patients (n=160) were divided into four treatment groups: information related to diabetes only, a personal self-management coach, a social support intervention and the final group was a coach and the social support intervention. The personal self-management coach gave information and advice related to diet and self-management goals. The social support intervention was a peer directed forum where all the members in this treatment could interact in real-time or to previously posted chat topics and were encouraged to do so daily. After three months, participants in both groups

with the social support intervention had significantly increased perceptions of support when compared to those in the information only group.<sup>56</sup>

McKay's study of the D-Net intervention was an internet based study of 78 patients with type 2 diabetes over 8 weeks.<sup>84</sup> Participants were randomly assigned to either an information only group or one that received personalized advice and feedback on goal setting and could post online messages to a goal coach and participate in peer group support areas. While there was an improvement in both groups with respect to physical activity level increase, those that used the peer support site and personal coach more often reported greater benefits such as more vigorous levels of physical activity and overall satisfaction with the program.<sup>84</sup> Glasgow's study included in the meta-analysis by Eysenbach was a continuation of the D-Net study that McKay, Glasgow and other colleagues conducted. Over time, the original findings reported diminished and all groups, information and peer support had improvement from baseline over time. Internet use for peer support also declined over time. The authors conclude that these effects might be a result of recruiting novice computer users and providing them with the computer and internet access as opposed to having individuals who were already familiar with the technology or who would self-select to participate in a support or peer group. Additionally, individuals were only in contact with other members of the D-Net study and did not have access to other websites or other groups, which may have increased use and perceived benefits.

There has not been robust evidence on the effectiveness of peer online support. Many studies are exploratory or descriptive, using many different

instruments and multiple comparisons making it difficult to find positive results. Studies are often underpowered with inadequate sample sizes.<sup>80</sup> More quantitative studies are needed to evaluate under which conditions and for whom online support groups are beneficial and how to maximize the effectiveness of such groups. Studies on peer online groups are few, as there is a lack of commercial or professional interest in evaluating the effects of such groups, particularly those that lack moderation by a health care professional.

The effectiveness of such groups on diabetes self-management also needs to be examined more thoroughly. In today's busy world, diabetes self-management may not be the patient's primary concern. People may be a "patient with diabetes" while they are with their health care provider, however this identity is low on the list of how they would define themselves outside of the health care environment.<sup>85</sup> Because one is not always in an environment that provides cues, support and services that are diabetes-specific, the use of online communication is one way that diabetes support and services can be provided in a timely, attractive and low-cost way.<sup>78,85</sup> The role of internet-based care as one solution to the problem of inadequate support needs to be assessed from the patient, provider, system and payer perspective. The ability of such groups to provide self-care support that reaches thousands of patients with minimal cost has ramifications for how diabetes care is provided.<sup>86</sup> The health care system as a whole lacks the funding and staff to proactively provide day to day support to persons with diabetes.<sup>85</sup> Extending daily support to patients with diabetes through online groups may result in the prevention of avoidable complications

and unnecessary treatment, which translates into cost savings for the system. Finally, it is important to know how online support groups are being used and if and how the interaction in such groups help motivate self-management behaviors.

### **Relationship between social identity and support groups**

Virtual communities are social spaces that are sustained through continuous communication between group members in an effort to meet mutual goals.<sup>43</sup> Virtual groups are often termed communities, implying a sense of personal responsibility or obligation to the group, as well as reciprocity between members. However, unlike local support groups which encourage member interaction and participation, a patient can belong to a virtual community and not interact initially, during each visit or at all.<sup>59</sup> The membership in virtual groups is voluntary and tenuous and can be initiated and terminated at any time.<sup>43</sup> Virtual communities through online groups are one means patients with chronic illness improve their quality of life. This sense of community is one that is chosen, instead of one into which an individual is born. This process is less stressful when done anonymously online, when compared to support groups that are held face-to-face. In virtual communities, the strength of contribution to the group is valued above physical features or the disabilities associated with the illness.<sup>56</sup> The individual that has body image concerns related to their chronic condition may be more at ease participating in group discussion online than in a setting that is face-to-face.

Despite the perception that online support groups provide anonymity and reprieve from disclosing personal information or physical disabilities, there can be a more personal aspect of these groups that allows for sharing more than just information regarding the illness. Self-esteem of support group members can be evident in certain ways. One such example is in the selection of a screen name, or identity. The person can opt to use an actual picture of them, or of a character that might represent their attitudes or strengths. Some sites encourage members to create profiles that include information about the individual that is illness-specific, such as years since diagnosis, type and stage of illness, if in remission, treatments used, and even clinical test results (i.e., such as HbA1c). Many messages that are posted have signature lines which can contain favorite quotes to convey humor, or even the patient's most recent HbA1c level to convey control of the illness. These "signatures" seem to convey pride in one's identity as a patient with control over his or her illness. A member with type 2 diabetes is not only someone with type 2 for 6 years that lives in Oklahoma, he becomes Joe type 2 with an HbA1c of 6.4 for the past 2 years. Pride in being able to maintain an acceptable hemoglobin A1c value for two years is evident in how Joe chooses to portray himself to other members of the group.

The member has the option of uploading personal photographs of themselves or family to share with the group and information about their other roles such as spouse, parent, etc. Many members personalize their site with favorite quotes, pictures of their pets and music. These profiles can be viewed by all members and allow the individual to provide another perspective of their

lives irrespective of the illness. Certain individuals might also include information regarding their success in treating and managing his or her condition in a tagline that appears when he or she leaves messages on the forum chat boards or on another member's profile. Group member status can be improved through the creation of group content. Active participation and posting in these groups can be one way to increase status and thus improve self-esteem.<sup>43</sup>

While the interactions and exchange of information may be similar between the online and face-to-face groups, there may be a greater likelihood that individuals that participate in face-to-face support groups will form social relationships and engage in social activities outside of the support group environment, particularly if other identities they possess (parent, occupation, recreation) are similar to another support group participant. Other streams of research have identified that the relationships formed in virtual groups are "weak tie" relationships that are characterized by daily interaction between two people that are not necessarily "close", i.e. neighbors, service providers, etc. However, it is found that these individuals can be more connected to each other and have more diverse social networks than those who do not belong to virtual groups. This characteristic of virtual groups can be a benefit for individuals with a busy lifestyle because it allows them to obtain support without requiring an investment in time and energy in cultivating other aspects of the relationship. While these relationships might not be long-term, some can develop into stronger ties through physical interaction outside of the virtual community. In a qualitative study done in older adults, it was found that caregivers in an online support network



perceived their relationships with others in the community as stronger than those with family members at times. The level of understanding and empathy is one such reason.<sup>76</sup>

This understanding and empathy is what might also attract individuals with chronic illness into such groups. Family and friends can only provide a certain level of support that does not include experiential support. Peer support includes this component and therefore might make the support more meaningful for the individual. There does not appear to be any empirical comparisons of the types of support a patient might receive and the impact of specific support on patient-reported outcomes.

The relationship between social identity and support group identity in this study is measured as the an interaction of social identity and support group identity to more effectively influence goal setting than social identity itself. For social identity, the group referred to is the whole of all type 2 diabetes in the United States. Membership in this group, including feelings of belongingness and attachment will be assessed. Support group identity assessed the same feelings, however with respect to the online support group and included more specific measures of self-esteem derived from membership, along with and value, pride and importance of being a member.

### **Goal Setting and Achievement**

Another aim of this study is to determine the effect of identity on goal setting and goal achievement. A goal is defined as “that which one wants to

accomplish; it concerns a valued, future end state.”<sup>87</sup> It is also the object or an aim of an action. There are different types of goals. Goals imposed by others, self-selected goals, goals set cooperatively and goals assigned with a rationale as to why the goal is desirable and/or achievable.<sup>88</sup> This research examines goals that are self-selected or set in cooperation with a health care provider or peer. Patients with type 2 diabetes have multiple lifestyle behaviors that can be the focus of goal setting.

Locke and Latham outline the four steps required for successful goal setting.<sup>89</sup> These steps include 1) recognizing the need for change as recognized by undergoing an emotional or affective experience; 2) establishing a goal, by determining goal specificity and difficulty; 3) monitoring goal-related activity, allowing for changes in effort, planning or strategy to achieve the goal; and 4) self-rewarding goal achievement to encourage setting other goals.

Many patients with diabetes lack the support they need to identify behavioral goals. Patients receive some support from their health care provider, but many times goals go unaddressed in the office visit because communication is focused on problems and other questions, or if goals are addressed, the patient does not receive enough support in-between visits to successfully achieve their goals.<sup>86</sup> Setting a goal with a health care provider during an office visit with no follow-up until the next office visit does not allow for the patient to receive any feedback from his or her provider, let alone support. Patients in need of support for behavior change goals can receive support from other patients via online support groups.

It is through peer interaction on patient support groups that the four steps of goal setting can occur. In viewing the struggles and hearing the stories of others, a patient might recognize himself and/or his need to change. Connecting with others on an emotional level in such groups can also be the stimulus to realize change in one's life is needed. Many support groups, such as Diabetes Daily and Daily Strength already have goal setting forums that allow patients with diabetes to execute steps 2 and 3 of the goal setting process Locke and Latham recommend. In addition to monitoring goal-related activity, these sites also provide another crucial step that Locke and Latham do not include, and that is feedback. Other support group members can track the progress one is making toward achieving her goal and provide encouragement, supportive feedback and share their achievements. Once the goal that is set is achieved, the online support group member is encouraged by the moderator or other members to move onward toward setting another goal, which is step 4 of the process.

Goal setting can be viewed as one mechanism of behavior change and maintenance strategies which also include skills development and education. It is important to understand the mechanisms that underlie behavior change and to determine under which conditions these mechanisms are most effective. There are few controlled studies of goal setting in the health behavior area, especially with regard to diabetes self-management behaviors. Those conducted in the health behavior area have focused on smoking cessation, seat belt use, condom use, sunscreen use, taking vitamins and exercise and diet change goals. The

majority of studies being conducted on goal setting are within business and employment environments and the goals examined are for job performance.<sup>90</sup>

Setting a goal is not enough to ensure achievement of that goal. The individual must also be interested in taking the steps necessary to achieve the goal, otherwise setting the goal is counterproductive and will likely have little effect. When there is no goal conflict present and the individual wants to achieve the goal, goal setting can improve performance of goal more so than if no goals were set.<sup>87</sup> The support group can aid in the process of goal setting and achievement

Goal setting theory states that setting specific goals and receiving performance feedback leads to better performance and goal achievement. At times it might be necessary to set sub-goals to achieve a goal that is more long-term. These sub-goals can be conceptualized as “tasks” that are proximal goals. Sub-goals are tangible and the social reward and self-gratification of distal goals can be too far away to cause hesitation or postponement of goal-related behaviors. For persons with diabetes, an example of a sub-goal or a proximal goal might be to increase daily consumption of fresh vegetables. This goal is a tangible behavior that can be monitored. The distal goal might be to lower overall hemoglobin A1c (HbA1c) and incorporating more vegetables into the diet can help keep blood glucose levels controlled and thus reduce one’s overall HbA1c. However, lowering HbA1c is a distal goal because it may take months for the patient to see an actual reduction that can be attributed to changes in the diet.

Sub-goals have also been shown to improve self-efficacy and satisfaction with performance.<sup>87</sup> Bandura demonstrates that perceptions of self-efficacy influence analytical thinking and problem solving on complex tasks and the development of effective strategies.<sup>91</sup> When self-efficacy is enhanced, the individual will produce greater effort and persist in goal-related behaviors, thus improving performance. The more confident the individual is, the higher the goals they set.

Goal setting theory is based on the idea that conscious goals influence action. The concept of self-efficacy is linked to goal setting in many ways. It has been shown that when goals are self-set, people with higher self-efficacy set higher goals and use better strategies to achieve the goals and also respond better to negative feedback than people with low self-efficacy.<sup>92</sup> Goal setting increases patient's self-efficacy in self-management behaviors. Goal setting support should help make the patient responsible and accountable for managing his health.<sup>93</sup> Peer support reinforces the goal setting process. The literature on goal setting states that setting goals is effective for changing and maintaining new behaviors. For patients with diabetes, whether they are newly diagnosed and have to change diet and lifestyle behaviors, or for longtime patients that are struggling to manage their condition, goal setting could play an important role in the self-management of this chronic condition.<sup>94</sup>

Setting more specific and challenging goals results in higher levels of success than do general or "do-my-best" goals. Allowing the individual to self-select their goals, as opposed to being assigned a goal by a health care provider,

has also been shown to provide more motivation to achieve the goal. Providing continuous feedback on goal-related outcomes is also a requirement for successful achievement.<sup>94</sup>

Studies have examined the role of goal setting in diabetes education and many have included aspects of the Social Cognitive Theory, including self-control, outcome expectancies, self-efficacy, and positive reinforcement. Core aspects of the goal setting process in educational interventions include recognizing/defining the problem, identifying a long-term outcome, setting behavioral goals to achieve the outcome, identifying barriers and facilitators to achieve the outcome, monitoring progress and receiving feedback, and making any necessary change to the process. Goal setting itself can be the method by which to self-manage the condition.<sup>95</sup> A survey study of 97 newly (between 6 and 18 months) diagnosed patients with type 2 diabetes found that 65% had set goals during a formal diabetes education program and 35% of these patients had changed their goals since the education program. The change in goal was significantly related to experiencing difficulty making changes in diet or monitoring blood glucose levels.<sup>95</sup> This finding indicates that setting and achieving goals while concurrently in a diabetes education program is much easier than when not in a program.

### **Relationship between support group participation and goals**

The support and accountability that the diabetes educator or other patients in a group education setting provide the patient might aid in the goal setting and

achievement process and when this support is no longer present, the patient is not able to meet previous goals and must adjust the goal accordingly. The study by Sprague also found that 68% of the study population reported having 2-4 goals, and that advice from a health care professional was related to diet, exercise and blood glucose monitoring goals.<sup>95</sup> This study demonstrates that setting goals was a useful tool in the self-management process, however, it is unclear what occurred after the educational process was complete and the factors that might have resulted in goal abandonment or goal change. Interestingly, the measures for self-management and goal setting were in part created from a focus group of individuals in support groups and the characteristics of these individuals might not match those of the test group in terms of motivation, co-morbidities, etc. However, these characteristics were not measured, so an accurate assessment cannot be made. Perhaps this study and the instrument constructed would be more applicable in the population such as the one targeted in this study.

Patients with type 2 diabetes have multiple lifestyle behaviors that can be the focus of goals. It is more effective to set behavior change goals than to set physiological status goals, i.e. to improve blood glucose levels. Instead the patient should focus on dietary change goals that might influence blood glucose levels. Behaviors are more directly under the individual's control and are related to effort, concentration and persistence than metabolic outcomes which can be subject to many other influences that may not be controllable. Goal commitment and confidence to achieve the goal are important to measure. In goal

achievement studies, determining the self-efficacy to perform the behavior and the reasons why self-efficacy is low are important aims (Strecher 1995).<sup>90</sup> Possible reasons for low self-efficacy for self-management behaviors for persons with diabetes might include a lack of support or a lack of information about medications or the effect of diet and exercise on blood glucose control. Online support groups can address both of these barriers and help increase feelings of self-efficacy toward the behavior as well as the frequency of the behavior itself. For the purposes of this study, general support, goal-specific self-efficacy, general self-esteem (confidence) and understanding of the disease will be assessed to ascertain if and why individuals might lack self-efficacy and how online support groups might influence self-efficacy.

Self-help or support groups can improve self-esteem through reciprocal caring. Self-efficacy, or being capable to execute behaviors is also promoted by support groups because these groups tend to reinforce behavior that is appropriate and some may provide mentors to participants that model the desired behaviors and offer support with coping. Feedback on goals also increases self-efficacy<sup>88</sup>, and for particular groups, such as Daily Strength, allowing other group members to leave comments and encouragement or tips to improve success, can improve the goal setting-goal achievement process.

One of the basic tenets of social identity theory is that individuals define and evaluate themselves in terms of the group. Inter-group social comparisons allow one to preserve self-esteem. Low self-esteem in turn can motivate social identification with a particular group, thus elevating self esteem and encouraging



behavior<sup>63</sup>, while individuals with high self-esteem may belong to the group, but set high goals for themselves, without influence from the group.<sup>96</sup> The findings from one study imply that self-esteem, both low and high, has influence on goals. For example, a newly diagnosed patient with diabetes may have low self-esteem as a result of feelings of anxiety and uncertainty about managing the condition. To combat this uncertainty, or as a result of this anxiety, he or she seeks information and support, perhaps joining a diabetes support group. The support group provides information that arms the patient with tools to manage his condition, and offers encouragement to reach goals (i.e. HbA1c <7) through behaviors such as diet, exercise and medication taking. This is one example of how identity can influence goal-setting.

Goals can also be related to identity in the sense that they take into account the individual's definitions of commitments and responsibilities in relation to other people and their social relationships with these people. There exists an identity hierarchy in each individual. Identity levels include the supernormal social identity that reflects an identity that requires extraordinary behavior and achievement; the restored self that reconstructs identities prior to the illness; the contingent personal identity that hinges on the uncertainty of identity due to the illness; and the salvaged self that one retains because that part of identity was valued at some point.<sup>26</sup> Other identities, such as mother, wife and teacher may supersede the illness identity, in terms of motivational influence to engage in self-care, or the roles associated with these other identities may cause the individual to push themselves beyond their bodily limitations.<sup>24</sup>

Goal achievement is facilitated by the importance the individual places on the outcomes that are expected from working towards a goal and the belief that the patient can attain a goal (self-efficacy).<sup>92</sup> Self-efficacy can be enhanced through role modeling or finding models with whom the person can identify and also by increasing persuasive communication that can improve the individual's confidence.<sup>92</sup> Motivation to achieve goals, whether they are generic in nature, i.e. to be healthy, or specific, i.e. to achieve an HbA1c value of 7.0 or less, can be influenced by self-esteem and group membership.

The influence of self-esteem on goal setting has been demonstrated in studies of employees<sup>96</sup>, and the same concepts can be applied to patients to encourage goal setting with respect to taking medications and achieving acceptable HbA1c levels. A strong social identity is a part of an individual's high self-esteem and can be viewed as a moderator of self-set goals. Social identification interacts with the self-esteem of in-group members to influence goals. Goal setting defines the basic motivation for and gives purpose to one's behavior.<sup>96</sup> Self-esteem (how favorable an individual's characteristic self-evaluation is) has also been linked to setting goals. Individuals with high self-esteem place more demand on their abilities to perform and set more difficult goals. In self-set goals (goals that the individual sets for himself), individuals, regardless of self-esteem, set equivalent goals.<sup>96</sup>

A study on 422 patients with type 2 diabetes with the objective of determining the frequency and effectiveness of goal choices in managing diabetes was conducted using mail and telephonic support over a period of six

months.<sup>94</sup> The hypotheses of the study were that self-selection of goals and behavioral specificity is key to enhancing persistence of goals. By allowing patients to choose their goal, the patient will choose the goal that corresponds to an area that they need the most improvement in and also will result in a greater change in behavior. Goals included to reduce fat intake (<30% of calories consumed per day), to increase fruit and vegetable consumption (5-9 per day) or to increase physical activity (150 minutes of moderate-intensity physical activity per week). Goals were selected, barriers were identified and strategies to overcome barriers using an interactive computer program. Goal-related feedback was given during a counseling session with a trained medical assistant. A follow-up phone call was conducted two weeks later to review progress and provide feedback. Almost half of the population chose activity goals, one quarter chose increase in fruit and vegetable consumption and to reduce fat intake. For each goal, there were significant differences whereby the individuals who selected a particular goal were different from those that did not, because they were not currently achieving that particular goal. All participants significantly reduced the amount of fat in their diet, but those that selected that goal had a larger decrease. Participants that chose to increase fruit and vegetable consumption significantly increased consumption. There was a significant increase in physical activity for participants that selected that goal. Some limitations of this study are that the goals selected for the study were very narrow and there were only three to choose from, which may have limited the population and also not represent the goals for all patients with diabetes. The “self-

selection” process used in the study and the limited number and scope of goals (dietary and physical activity) might not mimic a true self-selection process that would allow for even more specific goals.

The literature on goal setting states that setting goals is effective for changing and maintaining new behaviors. For patients with diabetes, whether they are newly diagnosed and have to change diet and lifestyle behaviors, or for longtime patients that are struggling to manage their condition, goal setting could play an important role in the self-management of this chronic condition.<sup>94</sup> Personality attributes most oft studied in persons with diabetes include locus of control, the self-concept or self-esteem, and coping mode. Research on self-concept has shown that positive self-esteem results in better psychosocial adjustment to diabetes. Positive self-concept has also been correlated with adherence<sup>97,98</sup>

Goal setting increases the patient's self-efficacy in self-management behaviors. Goal setting support should help make the patient responsible and accountable for managing his health.<sup>93</sup> Peer support reinforces the goal setting process. When monitoring goals, adjustments in strategies or effort may be needed over time. Feedback is important in this process and can improve patient self-efficacy.<sup>88</sup> (Webber) Self-efficacy is related to level of goal setting and achievement, such that individuals that are more self-efficacious set higher goals and perform better than those that lack self-efficacy.<sup>99</sup> Locke and Latham found an effect size of  $r=.39$  in a meta-analysis of 14 studies examining this relationship.<sup>89</sup>

Self-efficacy is sometimes a construct that is included in many models, and can be defined as an individual's judgment concerning their ability to monitor, plan and execute activities on a daily basis.<sup>100</sup> Self efficacy has received much empirical support in its relationship to health behaviors, particularly medication taking behaviors. Individuals with greater levels of self-efficacy were less likely to skip doses of medication. Self-efficacy explained 4-10% of the variance in diabetes self-care behaviors in a total of 309 patients with type 2 diabetes.<sup>100</sup> Self-efficacy was found to be a significant predictor of adherence to diabetes treatment for both insulin-dependent and non-insulin dependent patients with diabetes. Self-efficacy has been shown to predict behavior change that is maintained over a period of time. Self-efficacy was measured by asking the confidence level of the participants regarding adherence to a diabetes treatment regimen over an eight week period.<sup>101</sup> Self efficacy has received much empirical support in its relationship to health behaviors, particularly medication taking behaviors. Individuals with greater levels of self-efficacy were less likely to skip doses of medication. Self-efficacy explained 4-10% of the variance in diabetes self-care behaviors in a total of 309 patients with type 2 diabetes.<sup>100</sup>

Another study aim pertains to the relationship between identity and goal setting. Goals can be related to identity because they account for the individual's commitment and responsibility to other people, which can be preserved, if the person achieves the goal. For the purpose of this study, goals in the model and hypotheses refer to the patient's and potentially the group's goals with respect to

self-managing diabetes. This study intends to focus on the support that the patient receives from other patients with diabetes and diabetes educators and/or moderators of diabetes support groups. The hypotheses suggest that individuals who identify with a support group are more likely to socially identify with their illness, and receive the support necessary to increase self-esteem and self-efficacy to set goals.

Due to the nature of self-efficacy and the ability to modify one's self-efficacy, any interventions that center on improving self-efficacy can have tremendous implications for improving health outcomes for chronically ill patients.<sup>102</sup> As a possible intervention, incorporating the use of a support group in chronic disease management can improve self-efficacy in many ways. One such way is through the observation of others, which allows members to determine which behaviors are appropriate, and how to respond to others accordingly.<sup>91</sup> Self-efficacy has long played a role in behavior change, particularly in changes related to health maintenance. Self efficacy effects coping behaviors, and individuals that persist in subjectively threatening activities (such as taking medication or exercising) that are relatively safe will reinforce self-efficacy more so than those that stop these preventative behaviors prematurely.

The support group can improve self-efficacy in many ways. Through the observation of others, members can determine which behaviors are appropriate, and how to respond to others accordingly.<sup>91</sup> Self-efficacy has long played a role in behavior change, particularly in changes related to health maintenance. Self efficacy affects coping behaviors, and individuals that persist in subjectively

threatening activities (such as taking medication or exercising) that are relatively safe will reinforce self-efficacy more so than those that stop these preventative behaviors prematurely. Perceived self-efficacy influences how individuals choose to behave and how much effort they expend in the process and for how long they persist in this behavior despite barriers.<sup>103</sup> Observing others succeed at behaviors through their efforts can provide efficacy information, as well as having others verbally persuade oneself that they are capable of the behavior.

Another means by which support groups improve self-efficacy is through the concept of experiential knowledge. Defined by Borkman as the “wisdom and know-how gained from personal participation in a phenomenon [coupled with] a high degree of conviction that the insights learned from direct participation in a situation are truth”.<sup>104</sup> Support groups can be viewed as experiential learning communities that aid in the construction, application and distribution of experiential knowledge. As such, patients with a long-term illness can become experts in the experiential nature of managing the illness.<sup>58</sup> When a patient is supported by a program or group that promotes self-management, the sense of self-efficacy one has increases over time, which has potential positive health benefits such as physical and social functioning.<sup>58</sup>

## **Conclusion**

This chapter highlights studies that have evaluated the relationships between identity, goals and support groups. Self and identity can be used in

social and behavioral research to understand the social and behavioral factors associated with physical health and disease.<sup>105</sup>

Patients with type 2 diabetes manage 95% of their own care. It is imperative that patients participate in diabetes education after diagnosis in order to effectively manage their condition. Diabetes self-management education programs that are recognized by the American Diabetes Association focus on goal setting in the self-management process.<sup>95</sup> Through education, patients with diabetes can learn how to assume a more active role in self-management and become more motivated to achieve self-management goals.<sup>106</sup>

For effective diabetes self-management support, there needs to be a coordination of services and support to the patient provided between outpatient office visits. Internet-based peer support is one solution to the problem of inadequate support, allowing self-care support to reach thousands of patients with little or no costs to the patient or third-party payer. Online support groups can provide support in-between provider visits to assist in goal setting and goal achievement.<sup>86</sup> This is a viable alternative, as most care management programs lack the funding and staff to proactively provide day to day support to persons with diabetes.<sup>85</sup>

The literature does not provide conclusive evidence of the nature of the relationships between the constructs that are included in this study model: illness identity, social identity, goal setting, goal self-efficacy and goal achievement. Studies of support groups often fail to find the effect of the group, despite patient



and provider attitudes that the group has meaningful benefits. However, most of the studies often do not use standardized instruments to measure objective outcomes, instead using subjective measures of satisfaction as the only measure of the group's success. Many studies can be underpowered and thus the results obtained are not significant. The length of the study can also pose a concern, as many studies fail to examine the long-term effects of support groups. Support groups included in some studies are not always representative of the patient population, with the majority of participants being white middle class women. This makes it difficult to generalize the findings of the study. Not using a control group and randomizing patients to conditions are also methodological flaws common in these studies. Many studies are have limited time frames if longitudinal, and after the intervention period, the study did not continue, despite demonstrating significant benefits beyond the intervention period. When support is not continued and patients are not directed to other sources of support, there might be greater consequences if no support were given.

Therefore, it is imperative to conduct additional studies to further examine these relationships and to provide a more clear understanding of the implications of identity on self-managing chronic conditions, and what, if any, the influence is of peer support provided through online support groups has on this relationship.

To this end, the current study aims and hypotheses are:

**Aim 1: To determine the relationship between illness identity and social identity on goal setting and achievement in persons with type 2 diabetes.**

**Hypothesis 1.1** For individuals with diabetes, illness identity influences one's social identity.

**Hypothesis 1.2:** The association between illness identity and social identity is greater in individuals that belong to an online diabetes support group than those that do not.

**Hypothesis 1.3:** Social identity influences both lifestyle and medication goals.

**Hypothesis 1.4:** Social identity is positively associated with an increase in goal self-efficacy.

**Hypothesis 1.5:** The relationship between goal setting and goal achievement is mediated by goal self-efficacy.

**Aim 2: To determine the influence of support group identity on the relationship between social identity and goal setting in persons with type 2 diabetes.**

**Hypothesis 2.1:** The positive association between social identity and goal setting becomes stronger as the level of support group identity increases.

**Aim 3: To determine the influence of support group identity on the relationship between goal setting and goal achievement.**

**Hypothesis 3.1:** The positive association between goal setting and goal achievement becomes stronger as the level of support group identity increases.

**Hypothesis 3.2:** The level of support group identity increases patient's goal-related self-efficacy and thus strengthens the association between goal setting and goal achievement. As self-efficacy increases, goal achievement increases.

**Aim 4: To characterize the interactions that may occur within the support group network and use these findings to hypothesize relationships between these interactions and the benefits from such interactions on goal setting**

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## **CHAPTER 3**

### **METHODS**

#### **Chapter Overview**

The dissertation study is a cross-sectional study of the influence of support group participation on goal setting and achievement among patients with type 2 diabetes. In this chapter, the selection of methodological approach will be discussed. A description of the online survey, the main data source for the study, including the development process, will follow. Data method collection processes will be reviewed and the data analysis plan will be described.

#### **Selection of Methodological Approach**

The overall aim of this study is to determine the relationship between identity and goal setting in patients with type 2 diabetes, and if this relationship is strengthened by participation and identification with a type 2 diabetes online support group. Modes of data collection considered for the study included mail surveys, focus groups, face-to-face interviews and online surveys. Baruch and Kaplowitz both found that online, or web-based surveys had as high or higher response rates than traditional mail surveys.<sup>1, 2</sup> Furthermore, because the target population for this study was online support group users, this mode of recruiting subjects and collecting data seemed applicable. This method is also a more cost-effective means of conducting research.

The data analysis includes descriptive analysis and hypothesis testing. Structural equation modeling and moderated mediation analysis were the main statistical methods for hypothesis testing. Structural equation modeling (SEM) allows one to obtain results with reduced bias and measurement error. Measurement error in the variables is statistically controlled, allowing for the measurement of reciprocal effects. SEM assesses overall fit of the model, which is important because model fit equates the suitability of the model to the study data. SEM simultaneously tests all model variables to determine model fit. If the model fit is good, this supports the theorized study model. The moderating relationships in the model were tested using moderated mediation regression analyses due to the smaller sample size of support group users in the study population. Additional information on the analysis plan will be provided in the other sections.

### **Sample Size**

The required sample size was determined by statistical power analysis.

$$\text{Sample size} = \frac{Z^2 * (p) * (1-p)}{c^2}$$

$$\frac{(1.96)^2 (24,000,000) (1-24,000,000)}{.05}$$

Where:

Z = Z value (1.96 for 95% confidence level)

p = percentage picking a choice, expressed as decimal  
(.5 used for sample size needed)

c = confidence interval, expressed as decimal ( .05 = ±5)

Using the National Institutes of Health statistic that states that there are over 24 million adults over the age of 20 that have diabetes (both type 1, which is much rarer, and type 2), we can assume that a sample of at least 384 would be needed, with a confidence level of 95% and a confidence interval of  $\pm 5$ . Zoomerang® (the online survey tool that was used to create and disseminate the online survey. More information about Zoomerang® will be provided in the recruitment phase. ) uses a calculation to determine adequate sample size that is dependent on the number of completed responses desired, divided by the access rate (which is the number of respondents in the panel that fit the criteria), divided by the incidence level of type 2 diabetes. It was determined that using the above number of 384 respondents, there were enough respondents in the panel to meet the eligibility requirements.

The size of the sample required to achieve results that are acceptable also depends upon the type of statistical methods used. For this study, structural equation modeling (SEM) is used, and in Kline's book, *Principles and Practices of Structural Equation Modeling*, he refutes the necessity of having 20 subjects for every model parameter, instead suggesting 10 subjects for every parameter is acceptable.<sup>3</sup> Model parameters are determined by the total number of variances and co-variances of all exogenous latent variables, measurement errors, any disturbances, factor loadings or any direct effects on the indicators from other factors and the path coefficients or any other direct effects on latent endogenous factors from other factors.

In the proposed study model, there is one exogenous variable (illness identity), generating one variance. The rest of the five variables would be endogenous variables, generating five disturbances. If 5 of 6 latent variables are measured by at least 2 indicators, the number of factor loadings and measurement errors would be 10 and 12 respectively. Based on the proposed main model, there are 6 paths. Therefore, the total number of model parameters would be approximately 34. Thus a sample size of approximately 340 would be needed for the study.

### **Sample Selection**

Study participants were selected using Zoomerang®, which is an online survey tool executed by MarketTools®, a market research company. Zoomerang® assisted in this project by assembling a quality respondent panel that was representative of type 2 diabetes patients in the United States. The Zoomerang® panel is comprised of more than 2.5 million respondents that have been extensively profiled on over 500 different lifestyle, demographic and occupational attributes, including medical history. Demographic information that has already been collected from Zoomerang® on their panelists includes date of birth, race/ethnicity, occupation and education. Health and medical information that is already known for panel respondents include: body mass index, diet (restrictions, calories, carbohydrates, type), weight, exercise attitudes and frequency. The panelist must also identify any medical ailments including diabetes and co-morbid conditions of diabetes, such as hypertension, high cholesterol or heart disease. These are all variables of interest for this particular



study. The respondent provides Zoomerang® with this information, which is then verified. The validation process ensures that each respondent is authentic and also unique to the panel.

### **Inclusion**

Patients diagnosed with Type 2 diabetes

Patients taking both insulin and oral diabetes medications

Patients age 18 or older

Patients responsible for taking their own medication

Patients that are ambulatory (non-institutionalized)

Patients that can communicate in English (both written and oral)

### **Exclusion**

Patients with Type 1 diabetes

Patients with gestational diabetes (pregnant women)

Patients with cognitive impairments

Using the inclusion/exclusion criteria for the study, along with some screening questions, the panel respondents were recruited into two groups: type 2 diabetes patients that belong to a support group and type 2 diabetes patients that do not belong to a support group. Panel respondents were given a link to complete the survey online. Depending on the response from the initial email Zoomerang® sends out to potential respondents, 1-2 reminder emails were sent to non-responders. Once the survey was complete, the respondent received an incentive.

Zoomerang® services were used in both the pretest and the main study. Based upon the results of the pretest phase, and some issues in recruiting subjects, some changes were made to the data collection and recruitment procedures in the test phase. For both phases, it was requested that a sample consisting of individuals with type 2 diabetes over the age of 18 that is evenly distributed between females and males, and approximate an ethnic diversity equivalent to the racial demography of the overall type 2 diabetes population within the United States be recruited. Email invitations were sent out by Zoomerang® to approximately 1200 Zoomerang® panelists.

## **Data Collection**

### **Pilot study**

The instrument used in the study was pilot tested before being distributed to the test and pretest study population. The instrument was peer reviewed by faculty at the University of Michigan before it was piloted in a small group (n=5) of type 2 diabetes patients from a University of Michigan ambulatory care clinic in Brighton, MI. This clinic has a diabetes care program that includes individual disease management by a clinical pharmacist. Appointments usually consist of the pharmacist reviewing the patient's chart for test results (such as HbA1c), medication information, and other health care provider notes. The patient may also bring their medication taking and blood glucose monitoring logs, which the pharmacist can review to determine if the medication doses are appropriate and the blood glucose testing results are in the appropriate range. The pharmacist may make changes to the type and/or dose of medication prescribed and might

also make suggestions for diet and exercise. Often, the pharmacist requests that the patient share any self-management goals they have or to set a goal to work toward for the next appointment.

Patients included in this phase of the study were identified through a clinical pharmacist for inclusion. Inclusion criteria included the following: patient must be diagnosed with type 2 diabetes, patients must be age 18 or older, patients must be responsible for self-managing their diabetes (not solely dependent on another for self-management behaviors such as blood glucose monitoring, taking medications, etc), patients must be ambulatory (non-institutionalized), patients must be able to communicate in English (both written and oral). Patients with Type 1 diabetes or gestational diabetes (pregnant women) and patients with cognitive impairments were excluded from the study. Once these criteria were met, the clinical pharmacist notified patients of their eligibility to participate in the study and obtain verbal consent in-person. A sample of the subject recruitment script can be found in Appendix A. The pharmacist typically meets with patients in the diabetes clinic every 3-4 weeks. Upon verbal agreement to participate in the pilot study, participants were asked to read and sign a consent form. A copy of the consent form can be seen in Appendix A. The participant was then given a paper survey and a writing utensil to complete the survey in a private office area. Participants were asked to self-administer the survey, however the principal investigator remained in the room to assist as needed. Participants were directed to indicate any questions or terminology that is confusing either on the survey itself or in communicating with

the investigator at the completion of the survey. Participants had the option to provide feedback on the survey, however were not required to do so. Upon completion of the survey, participants received a \$10 gift card to Kroger grocery and pharmacy.

In addition to recruiting respondents at the clinic described above, respondents to represent online support groups were recruited through an online support group, Diabetes Daily®. Diabetes Daily® is a site that was created in 2005 and has over 20,000 members and has received over 3 million visits to the site since its creation. Created specifically for patients with type 2 diabetes, it has over 100 forums related to diabetes care and support, including research investigations. Permission to post a link to the survey was granted, and 7 individuals from the group completed the survey online and provided feedback on the survey.

### **Pretest**

In order to determine if the methods are sufficient to recruit a suitable patient population for comparison purposes and to conduct some exploratory factor analysis on the survey instrument, a pretest was conducted in a sample population of 100 individuals using Zoomerang®. The process of selection and recruitment varied for the different phases of the study, and will be described below.

## **Description of the Online Survey**

The mode of data collection for the dissertation study was an online survey. The survey questionnaire was developed based on previously published measures as well as items constructed using theory and pilot test responses. In the following section, the questionnaire will be described in detail and followed by an evaluation of the reliability and validity of the measures. The instrument consisted of validated survey measures and items, as well as some that have been adapted for use within this particular population to address the specific aims of the study.

## **Measures**

The survey was comprised of 66 questions for the non-support group users and 80 questions for the support group users. Each survey has several broad sections: 1) attitudes towards diabetes cause, treatment and control, 2) emotions related to having diabetes, 3) acceptance and denial of the illness, 4) how diabetes affects relationships with others, 5) how diabetes affects lifestyle, 6) identification with diabetes, both physical, cognitive, affective and evaluative, 7) relationships with various health care providers, 8) goal setting and goal achievement, and 9) sociodemographic and clinical information. The support group survey included questions regarding support group participation, types of role relationships within the support group, identification with the support group and evaluation of support group benefits. Some of the questions had more than one part. For both versions of the entire instrument, see Appendix B.

## Questions for Demographic and Diabetes Information

The demographic information collected in the questionnaire included: age, gender, ethnic origin/race, geographic residence, education, total annual family income, and marital status. For the non-support group users, information on gender and race/ethnicity was collected in the beginning of the survey, as screening questions to ensure a representative population. For the support group users, all demographic information was collected at the end of the survey. Diabetes-specific items included number of years since diagnosis, time frame since last hemoglobin A1c (HbA1c) test, the value of the last HbA1c test, and use of oral medications or insulin. These questions can be found at the end of both versions of the survey. All respondents were asked to provide the year in which they were diagnosed with type 2 diabetes, state when he/she last had his/her hemoglobin A1c measured and what the value was at that time, as well as to give an approximate average of HbA1c value over the last two years. Responses for the time frame included never had a HbA1c test, 1-2 years ago, 3, 6 or 12 months ago. Responses for the HbA1c value include don't remember, above 8.0, between 7.0 and 8.0, between 6.0 and 7.0, below 6.0 and have never had an HbA1c test. In addition, all respondents were queried on their use of oral diabetes medications and insulin. Variables along with the corresponding item number in the appropriate survey are listed below in table 3.1.

**Table 3.1: Description of Demographic and Diabetes variables in study**

<b>Variable Name</b>	<b>Description</b>	<b>Item in Support Group survey</b>	<b>Item in Non-Support Group survey</b>
Gender	Patient's gender	Item 69	Item 2
Race/ethnicity	Patient's race or ethnicity	Item 70	Item 3
Residence	US geographical region	Item 71	Item 57
Age	Patient's age	Item 72	Item 58
Marital Status	Patient's marital status	Item 78	Item 64
Income	Total annual household	Item 79	Item 65
Education	Highest level of education	Item 80	Item 66
Diagnosis	Number of years since	Item 73	Item 59
HbA1c	Last test date and value	Items 74 & 75	Items 60 & 61
Treatment	Oral medications and/or insulin use	Items 76 & 77	Items 62 & 63

### **Illness Identity variables**

Diabetes control beliefs were assessed on a 7-point Likert scale, with responses ranging from 1: not at all to 7: totally, with a midpoint of 4: moderately. Respondents were asked to which extent he or she believed the following statement about methods of controlling one's diabetes to be true. Control behaviors included monitoring blood glucose levels, eating healthy foods, avoiding certain foods, physical exercise, and taking medication. Beliefs referred to as "guilt" include the following items, "my diabetes must be a punishment for something I did in the past" and "I blame myself for having diabetes". Items

related to denial include, “I believe there is nothing wrong with me”, “ I am certain my diabetes will be cured”, and “I believe my diabetes will go away by itself”. The first of these items was used to assess if any denial regarding the diagnosis existed in any of the respondents. The other two items examined if any delusions about treating the illness or denial about the role of treatment were present.

Emotions related to being a person with diabetes were also assessed. Hopefulness despite having diabetes was the lone measure of positive emotion. Negative emotions included despair (“there is nothing I can do to help myself”, “I feel that nothing will ever be the same”), embarrassment or shame about having diabetes, envy directed towards other people in good health, worry and anger about diabetes and loneliness and isolation. For each of these items, the respondent was instructed to indicate how strongly the item(s) described how he or she felt about having diabetes on a 5 point scale (1: does not describe me at all to 5: describes me very well).

The support and assistance from non-support group members was also assessed. Three items honed in on the relationship one has with immediate family and friends asking them to respond on a scale from 1: not at all to 7: totally, the level of acceptance he or she receives from family and friends; the level of comfort family and friends express with the individual regarding his or her diabetes; and finally the amount of encouragement the individual receives from his or her family and friends. Expanding these questions to other individuals that may provide care and assistance, the survey asked the respondent to reflect on



the extent to which the following individuals assist in caring for your diabetes: spouse or significant other, children, other family, friends, doctor, nurse, pharmacist, a paid helper or “other”. The scale included 1: does not apply, 1: not at all, 4: moderately and 6: considerably. Related to this question then is how does assisting in the care of the respondent’s diabetes affects his or her relationship with the above listed individuals and also including employers and co-workers. The response scale was the same as for the above question.

### **Social Identity variables**

Diabetes impact on life was measured with two different perspectives in mind: a more present impact on life and a more future oriented view of life change as a result of having diabetes. Rearranging life priorities, seeking new meanings for life, accepting help from others, forming new friendships, making plans for the future, life interference and the perception one has of themselves in the context of being a person with diabetes. Again, response categories were a 5 point scale ranging from 1: does not describe me at all to 5: describes me very well.

For the concept of work-life balance, several questions were used. The context of the question was “Please indicate to what extent your diabetes and its treatment keeps you from doing the activities listed below”, and response categories were 1: not at all to 5: considerably. Activities included meeting work responsibilities, meeting household responsibilities, travelling, being active,

having good relationships, keeping a schedule, spending time with family and friends and having alone time.

Overall self-esteem was measured by using three items that included general life satisfaction, positive attitude toward self, and the ability to achieve goals that the individual set. The scale responses included 1=strongly agree; 3=neither agree nor disagree; 5=strongly agree. Social identity was measured using a previously validated social identity scale.<sup>4,5</sup> Participants were asked to respond to questions regarding membership in, and feelings of attachment and belongingness to the group of 24 million individuals in the United States with type 2 diabetes. Self-categorization by inclusion in the group measured cognitive identity and belongingness and attachment signal affective group identity. See table 3.2 for a complete description of the variable, the number of indicators for analysis and the corresponding survey measure.

**Table 3.2: Illness and Social Identity related variables in study**

<b>Variable Name</b>	<b>Description</b>	<b>Number of Indicators</b>	<b>Measure</b>
<b>Diabetes beliefs</b>	Control	2	Items 12,13,16 Items 14, 15
	Guilt	1	Items 2e, 2f
	Denial	1	Items 2a, 2b, 2d
<b>Diabetes emotions</b>	Hope(c), shame(g), envy(h), worry(j), anger(k), despair(l), loneliness(m)	3	Item 2c Items 2h, 2j, 2k Items 2g, 2l, 2m
<b>Diabetes impact on life</b>	Present	2	Items 8,10 Items 9,11
	Future	2	Items 3, 4, 5 Items 6, 7
<b>Social identification</b>	Identification with other diabetics	1	Items 27, 28, 29
<b>Relationship impact</b>	Relationships with others	2	Items 17, 18 Item 19
<b>General Self-esteem</b>	Global measure	1	Items 30, 31

**Goal related variables in the study**

Goal setting in this study refers to not necessarily the act of setting a goal per se, but more to the extent to which certain self-management behaviors are personal goals of the individual. Goal setting was assessed on a scale of 1: not a goal at all for me to 5: a strong goal for me, with 3: a moderate goal for me serving as the midpoint. This measure not only indicates whether or not the behavior in question is a goal or not for the individual, it also indicates the strength of the goal in question. Self-management behaviors that were assessed as goals in this study include: monitoring blood glucose levels, eating healthy

foods every day, avoiding the consumption of certain foods every day, engaging in physical activity regularly, conducting foot exams regularly, and taking diabetes medications as prescribed. For each of these behaviors, self-efficacy for each behavior was measured as a function of degree of confidence one felt toward achieving each behavior. This too was a 5 point scale with responses ranging from 1: not at all confident to 5: very confident.

Goal achievement was examined over a week long period, using the week prior to taking the survey as the timeframe to rate goal achievement. For each of the behaviors one could engage in during the last week, respondents could select the following options 1: not a goal of mine; 2: did not achieve this goal any day in the past week; 3: achieved this goal 1-2 days in the past week; 4: achieved this goal 3-4 days in the past week; 5: achieved this goal 5-6 days in the past week and 6: achieved this goal every day in the past week. In addition to these three variables, goal setting with various health care providers was assessed in the survey. Using a yes or no format, respondents were asked if goal setting was discussed at any visit with the following health care providers: general family physician, nurse, physician assistant, diabetes specialist (endocrinologist), and a pharmacist. Refer to table 3.3 for more information pertaining to the measurement of goal related variables in the study.

**Table 3.3: Goal related variables in study**

<b>Variable Name</b>	<b>Description</b>	<b>Number of Indicators</b>	<b>Measure</b>
<b>Goal setting</b>	Types of goals and strength of goals	2 Lifestyle 1 Medication	Q36a-e Q38f
<b>Goal self-efficacy</b>	Confidence to achieve specific goals	2 Lifestyle 1 Medication	Q40a-e
<b>Goal achievement</b>	Measured over past week	2 Lifestyle 1 Medication	Q42; Q43, Q44 Q45; Q46 Q47
<b>Discussion of goals with provider</b>	In any visit over the past three months	NA	Q35a-f

### **Support group identity and participation variables**

Type 2 diabetes support group participation was used to divide the sample population into two groups: those that belonged to online groups and those that do not. The question also asked the respondent to indicate if he/she had ever belonged to a face-to-face support group, however these individuals would be included with those that did not belong to an online group and would answer only the questions posed to this group. Current and previous online support group members were asked to indicate for how many online support groups he/she was a registered member, to name which group was the one that he/she visited the most often and then to indicate how often he/she visited that site on a daily, weekly, monthly and yearly basis. It was from the final question about frequency of usage that the levels of participation (low to high) groupings were determined.

Support group members were asked what types of activities they engaged in while visiting the site (participate in support forums or chat rooms, read blogs

or topics posted by others, post a blog or topic, respond to blogs or topics posted by others, search for diabetes-related information on treatment, search for diabetes-related information on nutrition, set a diabetes-related goal and monitor progress toward goal) and how often (have never done this=0, almost never=1, moderately often=3, very often=5) using a 6 point semantic differential scale. This same question was asked of non-online support group users, only it was posed as how likely on a 5-point scale of not at all likely to very likely, non-members would participate in the same activities listed above.

Support group members were asked a series of questions regarding their identity with the support group. Questions included to what extent they identify with the group, degree of overlap between group image and self-image, level of involvement, strength of attachment, belongingness, and commitment, degree or respect, admiration and self-worth associated with support group membership.

Finally, the perceived benefits of membership (sharing problems, receiving support, receiving advice, receiving information, setting goals, improving confidence, receiving goal-related feedback) were assessed of support group members. Likewise, non-support group members were asked to rate the extent to which they believed that membership in an online diabetes support group would provide the following benefits. Some of these items were adapted from a scale used by Barrera & Glasgow in a study they conducted that measured the emotional support, advice and information one receives from online support groups.

## **Support group identity variables**

The previously validated social identity scale that has been used by Ellemers and Bergami & Bagozzi has been adapted for use in this study.<sup>4,5</sup> Ellemers's Social identity scale consists of three components that comprise one's social identity.<sup>4</sup> The first component is a cognitive awareness of one's membership in a group and the self-categorization that results. The emotional component refers to the affective feelings of commitment that one has for the group. Identification with, involvement in and attachment to are ways to measure affective commitment. The final component is an evaluative component that refers to group self-esteem and can carry a positive or negative connotation. This also measures the individual's feelings of self-worth that result from membership in the group.

Adapting a scale used by Bergami & Bagozzi, respondents were asked the following questions: 1) To what extent do you identify with your diabetes support group?<sup>5</sup> A five point response scale ranging from "don't identify at all to "identify very much with" was used. 2) To what extent does your own self-image overlap with the image of those in the support group? Again a five point response scale was used with the following anchors "no overlap at all to "nearly total overlap".

Affective social identity was assessed using a scale validated by Allen & Meyer and adapted for use in this particular group.<sup>6</sup> The first item was "How attached are you to your diabetes support group?", responses ranged from "not

at all attached to “very much attached”. Feelings of belongingness to the support group were assessed on a range from “not strong at all” to “very strong”.

Evaluative social identity questions were taken from a scale used by Luhtanen & Crocker to assess group identity.<sup>7</sup> Using a five point scale ranging from “doesn’t describe me at all” to “describes me very much”, each respondent made two separate judgements about whether or not he or she was a *valuable* and *important* member of his or her support group.

Group self-esteem items related to the feelings of admiration and self-worth one attributed to his or her membership in his or her online support group, with responses ranging from 1: very little to 5: a lot.

**Table 3.4: Support group identity and participation variables in study**

<b>Variable Name</b>	<b>Description</b>	<b>Number of Indicators</b>	<b>Measure</b>
<b>Support group participation</b>			
<b>Frequency</b>	# of visits to site	NA	Item 53
<b>Activity participation</b>	Chat, blogs, forums, searching for info	2	Items 54b-d Items 54e-g
<b>Interaction</b>	Console, confide, encourage, etc.	2	Items 56a-f
<b>Support group identity</b>			
<b>Cognitive SI</b>	Awareness of membership	2	Items 57a-b, 58, 59, 67e-g
<b>Affective SI</b>	Emotional commitment	2	Items 61, 62, 63
<b>Evaluative SI</b>	Self-esteem resulting from group involvement	2	Items 57c-e, 60, 67a-b
<b>Group Self-esteem</b>	Respect, admiration, self-worth from membership	2	Items 64, 65, 66, 67c-d



## **Other support group variables**

Aim 4 of this study is an exploration of the different types of interactions, benefits and outcomes of interactions, role relationships (support giver versus support receiver) and other behaviors such as searching and setting goals that can occur in an online support group. Interactions that are examined include: participation in support forums and chat rooms, reading blogs, posting blogs or discussion topics and responding to others blogs or posted topics. In addition, behaviors such as searching for treatment information and nutrition information and setting a diabetes-related goal and monitoring goal progress are also included. Engagement in these behaviors and interactions were rated on a scale of 1: has never done this to 6: have done this very often. Role relationships within the support group were also examined. There are two types of roles a member can play in an interaction that takes place within the online support group: provider of support or the receiver of support (often the seeker of support). To assess the frequency of support received, the survey asks the respondent on a scale from 1: this has never happened to 5: happens a lot, whether another member has shown empathy, provided consolation or encouragement, reassures one, confides in you or pays you a compliment. To assess frequency of providing support, the same scale was used. Behaviors of providing support include sharing one's illness experience with other members, offering guidance and support and serving as a role model to other support group members.

Benefits of being in an online support group that were assessed include reassurance, as measured by "you see yourself in the experiences other

members post” or “you feel as though you are not the only one”. Scale responses include 1: this has never happened; 2: happens sometimes; 3: happens regularly; 4: happens often; 5: happens a lot.

Related to benefits of support group membership are outcomes of support group participation. The respondent was instructed to indicate the extent to which the following statements were true on a scale of 1: not at all true to 5: very true. Statements included: “provided you with useful diabetes-related advice”, “provided you with useful diabetes-related information”, “helped you set goals to self-manage your diabetes”, “improved your confidence to achieve diabetes-related goals”, “increased your acceptance of diabetes”, “provided feedback and encouragement on goal-related behavior”, “made you feel better prepared for your next appointment with a healthcare provider” and “increased your feelings of self-worth”.

### **Survey administration**

Two different versions of the survey were administered to two groups of type 2 diabetes patients: an online support group user survey and a non-online support group user survey. For both versions, informed consent was obtained via a statement provided at the beginning of the questionnaire. The text of this consent form was the same as the one used in the pilot test, however, there was no line for a signature. The subject was informed that responding to the survey items implied that the subject has provided informed consent. Contact information was provided for any questions or concerns regarding participation in

the study. The research protocol for this study was implemented with approval from the University of Michigan Institutional Review Board Medical division.

### **Incentives**

Past research has shown that incentives help increase survey response rates, and that incentive effects are stable across various study characteristics.<sup>8-</sup>  
<sup>10</sup> Once people have initiated a survey, they are more likely to finish the survey if an incentive is offered. For the pilot test, a \$10 gift card was given to the participant immediately following completion of the survey. For the pretest participants, Zoomerang® provided each participant with 50 “zoom” points upon completion of the survey to be used as merchandise credit. In the test phase, non-support group users were recruited by Zoomerang® and as part of the Zoomerang® panel, participants also received points. For support group users, whom were not a part of the Zoomerang® panel, each respondent was given the option to receive a \$10 Visa giftcard or donate his or her incentive to the American Diabetes Association® general research fund.

### **Analysis Plan**

The data analyses include the descriptive analysis, an evaluation of the instrument (and all of its versions), a brief evaluation of the impact of non-response bias, and the hypothesis testing. The data were analyzed using Pearson’s correlations coefficients, factor analysis, reliability analysis, factorial ANOVA, t-tests and moderated mediated regression. The primary statistical method used was structural equation modeling (SEM). The variables in the

study were presented in Tables 3.1, 3.2, 3.3 and 3.4. Descriptive statistics, including means, standard deviations and distributions were estimated for all variables in the study to characterize the sample. In the following sections, evaluation of instruments, which includes evaluation of reliability and validity, the assessment of non-response bias and hypothesis testing are discussed.

### **Evaluation of Non-response Bias**

Due to the nature of the study and the use of an online panel, non-response rate tracking is difficult to determine in most large online support group communities.<sup>11</sup> Self-selection bias may also occur, whereby certain individuals are more likely to participate in online surveys, while others typically ignore such requests, resulting in systematic bias.<sup>12</sup>

### **Construct Validation**

Construct validation is the process whereby the psychometric properties of a measure or scale are assessed to determine if they are actually measuring the theorized model construct. Construct validation of the instrument was conducted by establishing the correlations of the measures with the related variables as stated in the theory. Construct validity was also established by comparing the responses of the different groups of participants. Convergent validity is the assessment of the relation of the measures of constructs. Those that theoretically should be related to one another should be observed to be related to each other so that there is correspondence or convergence between similar constructs. Convergent validity was assessed by measuring the consistency

across indicators and the different methods of measurement such as interview and self-reports. To test construct (convergent) validity of the scales, Pearson's correlations were used to test the relationship between the independent variables and the dependent variables.

### **Reliability Analyses**

Reliability analyses were conducted for each measure of each construct in the study. Existing subscales and measures were employed in the final instrument. For the direct measures, reliability was established using an index of internal consistency. This will determine whether the items in the scale are measuring the same construct. The reliability of indirect measures will not use the same internal consistency criterion, because people can logically have positive and negative beliefs about diabetes. Therefore, it may not make sense to eliminate some of these beliefs from the overall measure on the basis of low or negative correlations among them. Cronbach's alpha was used as an indicator of consistency, whereby a level of 0.7 deemed the item acceptable and if the deletion of a particular item does not improve the Cronbach's alpha considerably that item was retained.

### **Construct/Variable Creation and Scoring**

Computations for model construct indicators were made based upon results for both exploratory and confirmatory factor analyses. The variables that were parceled into various indicators can be viewed in Tables 3.2, 3.3 and 3.4. Indicators with more than one item were parceled by summing the scores for

each item and then dividing that score by the number of items in the indicator. For individuals with only one item response missing, the mean response score for that item across all other responses was computed and assigned.

### **Factor Analysis**

As the survey instrument was adapted for use in this particular population, exploratory factor analysis was conducted on the pretest measure to test the individual measures of the survey instrument and their relationship to the constructs to be tested. This analysis was used to identify underlying commonalities, or factors, that are mainly the cause of co-variation in the data. The Maximum Likelihood Method of extraction with a Promax rotation was used. Missing items were addressed using list-wise deletion and the absolute value was set at 0.25. These techniques are used to maximize the variance within individual items so that items can be attributed to a particular factor. Factor loadings were then examined to identify which of the survey items loaded on each of the underlying factors. The value of the item factor loadings was assessed for inclusion in the factor. The conceptual meaning of the factors was derived from the types of items that loaded upon the factors, and the factors were then labeled. This made it easier to distinguish the differences in the items that loaded on the opposite factor(s). Total item correlations and internal consistency were examined to determine the homogeneity of the factors.

Confirmatory factor analysis (CFA) was then used to test particular hypotheses and also to test the specified full model to determine fit. Values for

chi-square ( $\chi^2$ ), degrees of freedom (df), root mean square error of approximation (RMSEA), the non-normed fit index (NNFI), comparative fit index (CFI) and the root mean square residual (RMR) were evaluated as evidence of convergent validity. Jaccard and Wan recommend that researchers define model fit using results of at least three fit tests, while Kline recommends at least four tests, such as chi-square; GFI, NFI, or CFI; NNFI; and SRMR.<sup>3,13</sup> For this study we will report results from the five tests listed above. These fit criteria will now be discussed.

The root mean square error of approximation (RMSEA) is the discrepancy per degree of freedom. RMSEA can correct for model complexity (penalizes for lack of parsimony) by computing average lack of fit per degree of freedom. There is good model fit if RMSEA less than or equal to .05. There is adequate fit if RMSEA is less than or equal to 0.08. Hu and Bentler have recommended using a cutoff of no higher than 0.06 for good model fit.<sup>14</sup>

The non-normed fit index or NNFI as it is abbreviated is also known as the Tucker-Lewis index. This fit index is relatively independent of sample size. TLI is computed as by using the chi-square values for the given and null model and the degrees of freedom. NNFI close to 1 indicates a good fit. Hu and Bentler have recommended that interpretations of good model fit use .95 as the cutoff. NNFI values below 0.90 indicate a need to re-specify the model.<sup>14</sup>

The comparative fit index, CFI, also known as the Bentler Comparative Fit Index compares the existing model fit with a null model which assumes the

indicator and latent variables in the model are uncorrelated. This comparison is done by examining the covariance matrix predicted by the model to the observed covariance matrix, and then compares the null model with the observed covariance matrix, to determine the amount of the lack of fit which is accounted for by going from the null model to the researcher's SEM model. Because CFI and RMSEA are fit indices that are not dependent on sample size (Fan, Thompson, and Wang, 1999), they are often used.<sup>15</sup> CFI values can range from 0 to 1, and a CFI value close to 1 indicates a very good fit.

Root mean square residual (RMR) equates to the mean absolute value of the covariance residuals. The closer RMR is to 0, the better the model fit. There are many cut-offs used for reporting good model fit in the literature. The most widely used rule is RMR should be at least less than 0.10, with values below 0.05, designating a well-fitting model.

In addition, good fit indices will provide support for the construct validity of the individual constructs in the model. The reliabilities of the constructs were reported using Cronbach's alpha values. To confirm discriminant validity among the constructs, correlations among all the variables were examined.

The associations between the dimensions of illness identity (beliefs and emotions) were assessed by calculating Pearson's correlation coefficients to determine if the dimensions of illness identity have any impact on the social identification of diabetes or the participant's self esteem. Pearson's correlation coefficient is used to determine the association between two continuous



variables. A positive coefficient value (values beyond 0.7) indicates a strong association. It is theorized that an increase in an illness identity variable score is associated with an increase in a social identification of diabetes variable score. If the correlation score is negative, an increase in one variable score is correlated with a decrease in the second variable score. Correlation tests were conducted in SPSS v. 17.0.

Descriptive statistics were used to determine means and standard deviations of all constructs as well as age, gender, marital status, level of education, and income. The means of the all items included on all scales used in the study produced a composite score. Cronbach's alpha was reported for these scores.

## Hypothesis Testing

**Aim 1: To determine the relationship between illness identity and social identity on goal setting and achievement in persons with type 2 diabetes.**

**Hypothesis 1.1:** For individuals with diabetes, illness identity influences one's social identity.

**Hypothesis 1.2:** The association between illness identity and social identity is greater in individuals that belong to an online diabetes support group than those that do not.

**Hypothesis 1.3:** Social identity influences both lifestyle and medication goals.

**Hypothesis 1.4:** Social identity is positively associated with an increase in goal self-efficacy.

**Hypothesis 1.5:** The relationship between goal setting and goal achievement is mediated by goal self-efficacy.

**Aim 2: To determine the influence of support group identity on the relationship between social identity and goal setting in persons with type 2 diabetes.**

**Hypothesis 2.1:** The positive association between social identity and goal setting becomes stronger as the level of support group identity increases.

**Aim 3: To determine the influence of support group identity on the relationship between goal setting and goal achievement.**

**Hypothesis 3.1:** The positive association between goal setting and goal achievement becomes stronger as the level of support group identity increases.

**Hypothesis 3.2:** The level of support group identity increases patient's goal-related self-efficacy and thus strengthens the association between goal setting and goal achievement. As self-efficacy increases, goal achievement increases.

**Aim 4: To characterize the interactions that occurs within the support group network and use these findings to hypothesize relationships between these interactions and the benefits from such interactions on goal setting.**

There are three main relationships that the study examines; the relationship between illness identity and social identity, the relationship between identity and goal setting and the relationship between goal setting and goal achievement. In the last two relationships, support group identity is proposed to moderate both relationships, strengthening the relationship between the two variables.

The first aim of this study is to assess the model fit for each study group. The main model hypothesizes that illness identity influences social identity which in turn influences goal setting. The relationship between goal setting and goal achievement is shown to be mediated by goal self-efficacy in the main model. While regression can be used to assess these relationships, this type of analysis does not account for all measurement error and cannot estimate reciprocal effects between model variables. As such, structural equation modeling (SEM) using LISREL 8.0 created by Jöreskog and Sörbom in 1997 was used to test the relationship paths in the main model. This technique is used to confirm theoretical models by testing the relationships between both observed variables and unmeasured latent constructs (which are indicated by multiple observed variables).

Model fit will be assessed using chi-square, degrees of freedom (df), RMSEA, NNFI and CFI. Acceptable ranges for these values to determine goodness of fit are as follows: RMSEA of 0.10 or lower, a NNFI or CFI value of 0.90 or greater and an RMR of 0.08 or lower. A lower chi square value and a non-significant or high p value (0.5 or greater) would indicate a better fitting

model. These values are considered acceptable indicators of good model fit (ref). This analyses will be run in both groups, support-group users (n=133) and non-support group users (n=253).

After determining model fit, a multiple groups analysis was conducted to test for measurement invariance across the two main study groups, specifically for significant differences in the models parameters. This test is necessitated when there is consistency in the model parameters across the two groups. Using the baseline multiple groups model chi square value, the model is ran multiple times, each time with a different parameter constrained. The chi-square values of these constrained models are then subtracted from the baseline model to produce a chi-square difference statistic. If this statistic is not significant (defined as a value about 3.84) this signifies that the model has measurement invariance across groups and thus applies across both groups.<sup>17,18</sup>

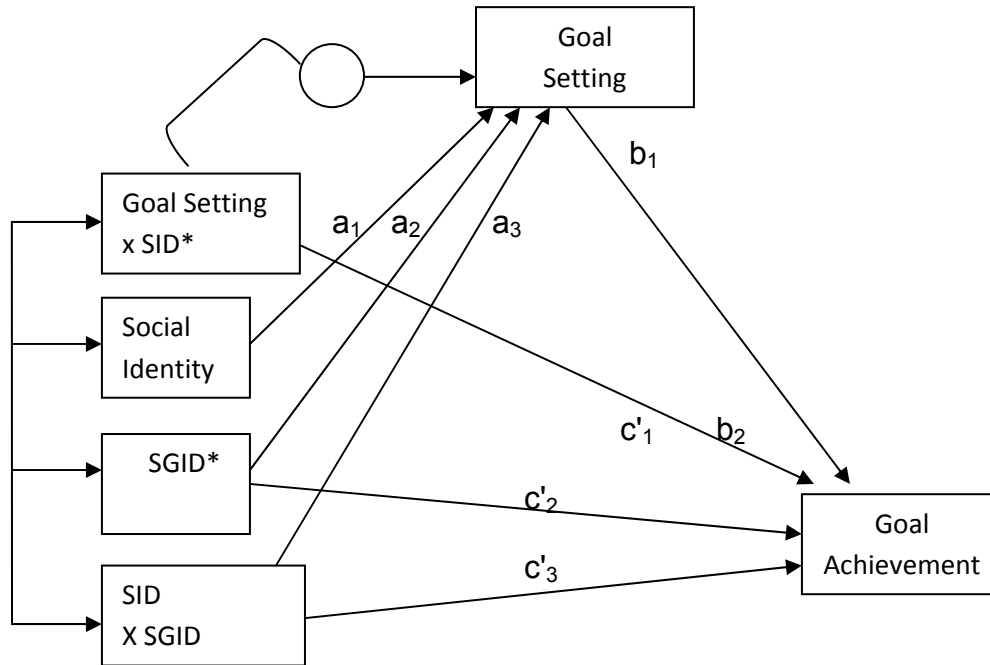
The moderating effect of identity with a support group on the relationship between social identity and goal setting and goal setting and goal achievement was tested using moderated mediation analysis. The second and third study objectives, both theorize that the relationship between social identity and goal setting and the relationship between goal setting and goal achievement are moderated by support group identity. For the purposes of this study, the moderator variable (level of support group identity) is a quantitative variable that will affect the zero-order correlation between identity and goal setting and goal setting and goal achievement. Support group identity scores are computed for each respondent using response scores from items measuring support group

evaluative, cognitive and affective attachment to the group, in addition to support group self-esteem. Moderated mediation measures and tests the differential effect of identity on goal setting and then goal setting on goal achievement as a function of support group identity scores.

Moderated mediation analyses, also known as Modmed, is an analyses of the conditional indirect effects in a model.<sup>19</sup> Mediation is an indirect effect whereby the causal effect on an independent variable on the dependent variable is transmitted by a mediator variable. A mediation effect can vary in differing contexts and for different groups of individuals. Moderation occurs when the magnitude of the relationship between two variables is dependent on a third variable.<sup>18</sup> If the moderator is measured on a ratio or interval scale, this may too determine the strength of the indirect effect of a mediator. Conditional indirect effects can be viewed as the strength of an indirect effect at a particular value(s) of a moderator.<sup>19</sup> This model tests when both the “a” and the “b” paths are moderated by W. This conditional direct effect is quantified as:

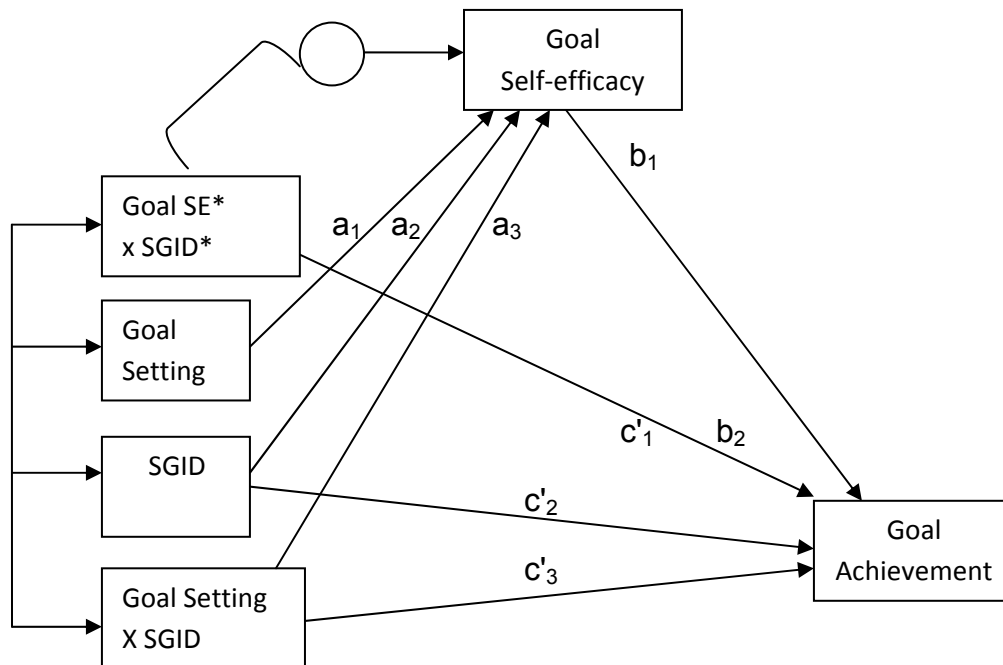
**$F(\hat{\theta}/W) = (\hat{a}_1 + \hat{a}_3W) (\hat{b}_1 + \hat{b}_2W)$**  in the following models.

**Figure 3.1: Hypothesized moderated mediation model for Aim 2**



\*SID=social identity SGID=support group identity

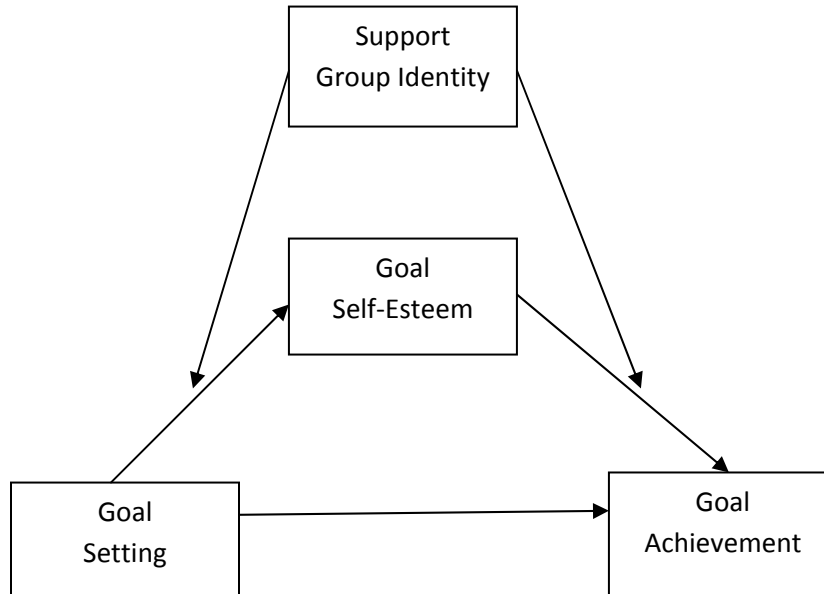
**Figure 3.2: Hypothesized moderated mediation model for Aim 3**



\*SE=self-efficacy SGID=support group identity

In this study, Moderated Mediation analyses were used to assess the strength of an indirect effect (mediation) that is dependent upon the value of the moderator (support group identity score). As such, simple mediation analyses using standardized regression techniques such as least-squares or maximum likelihood were not deemed appropriate. There has been some confusion as well surrounding the use of moderated mediation analyses versus mediated moderation analyses. The latter analyses involves showing a moderated interactive effect between the independent variable and the moderator on the dependent variable and then introducing a mediator of that effect.<sup>20</sup> However, in our study Aim 1 testes the effect of goal setting on goal achievement transmitted through goal self-efficacy, or in other words, a mediated relationship. After this analysis, support group identity was hypothesized to moderate the indirect effect and strengthen the mediated relationships at certain values (i.e. high scores of support group identity). Because the initial test of the model was examining possible mediation and then a moderating effect was examined, the analysis is moderated mediation. We can conclude that moderated mediation has occurred when the strength of the indirect effect (mediation) is dependent on the level of the moderator. For this study, moderated mediation was tested using the SPSS regression macro provided by Preacher and Hayes for the fifth model example. See figure 3.3 for a depiction of this model. In this model, W=support group identity.

**Figure 3.3: Preacher and Hayes model**



This model has been used instead of other models suggested by Preacher and Hayes because in this model, support group identity (SGID) is shown to moderate both of the relationships between goal setting and goal self-efficacy and goal self-efficacy and goal achievement.

Furthermore, quantification of the indirect effect can be investigated at various levels of the moderator to provide a formal hypothesis test.<sup>21</sup> The null hypothesis of no conditional indirect effects is tested by using bootstrap sampling distributions to generate confidence intervals for the conditional indirect effect. In this procedure, the sample is conceptualized as a pseudo-population that represents the broader population from which the sample was drawn and the sampling distribution is generated by calculating the statistic of interest in multiple



resamples of the data set.<sup>19</sup> The confidence intervals that result from this test will be presented. We can reject the null hypothesis stated above if the confidence interval does not contain 0, which would indicate that an indirect effect can be deemed different from zero if zero is not inside the upper and lower bounds. A Sobel test can be used when bootstrapping estimates are not able to be conducted.<sup>20</sup> The Sobel test was created by Sobel in 1982 to provide an approximate significance test for the indirect effect of the independent variable on the dependent variable via the mediator.<sup>20</sup> The exact formula, given multivariate normality for the standard error of the indirect effect or  $ab$ , is this:

$$z = \frac{a*b}{\text{SQRT}(b^2*s_a^2 + a^2*s_b^2)}^{21}$$

In addition to examining the role of identity in the above relationships, this study explored the impact of the frequency of participation on goal setting and achievement. Support group participation is an ordinal, or categorical, variable that was defined as either high or low. T-tests for high versus low interaction for participation in support group were conducted. Examination of possible interactions between participation in a support group and social identity were analyzed using a 2x2 Analysis of Variance (ANOVA), using established cut-points. Those participants that identified as belonging to a support group were asked how often he or she visits any online support groups. Responses ranged from *once, but never again* to *more than once a day*. High participation in a support group was determined by responses including: *visit 2-3 times a month, visit about once a week, visit about 2-4 times a week, visit about 5-7 times a week, once a day and more than once a day*. Low participation included the

following responses: *once, but never again, visit about 1-4 times a year, visit about 5-8 times a year and visit about 9-12 times a year (monthly)*. Support group identity scores were created by summing the responses from the items measuring support group self-esteem and support group cognitive, affective and emotional social identity items. Support group identity scores ranged from 1-5. Moderation will be indicated by an interaction effect. If support group participation and identity interact to cause (or increase) goal setting, the simple effects of identity across the levels of support group participation will be measured.

The last aim will be analyzed using descriptive statistics, t-tests and ANOVA to determine the relationships between support group members demographics, level of identity and participation, and types of interaction and the subsequent benefits and outcomes associated with those interactions.

### **Pilot Test and Pretest Results**

Prior to the presentation of the main study results, the results of the pilot test and pretest results will be described. The sample demographics, descriptive results of all variables used in the study and any changes that were made to the final survey instrument based upon the feedback provided in both phases will be presented. Any changes made to the study model based upon factor analysis and reliability analyses will also be presented.

### **Pilot test results**

Using inclusion/exclusion criteria similar to that of the final survey, the pilot test was conducted in two patient populations. The first population (n=5) was

taken from an ambulatory care clinic in the University of Michigan Health Systems. The survey was administered by the principal investigator after the patient was recruited by a clinical pharmacist during a diabetes disease management appointment. Those agreeing to participate signed an informed consent form. (Appendix A) Patients were asked to record their responses with a pen on a paper survey. Each survey was assigned a study identification number. The second population (n=10) was recruited from an online diabetes support group, named Diabetes Daily®. The survey was posted electronically on a diabetes research forum and online support group members could click a link that would allow them to complete the survey through Zoomerang® on their computer. Zoomerang® then recorded the responses, which were accessible for analysis. The responses from the ambulatory care patient population were also recorded through Zoomerang® to allow for a comparison of results and to give an overall picture of the patient population.

### **Demographics of the pilot test population (n=15)**

The population was 46.7% (n=7) female and 53.3% (n=8) male. The majority of the population was White (86.7%, n=13) with one Hispanic and one Native American subject. Ages ranged from 33 to 66. Over half of the population was married, more than a quarter never married and one-fifth were either separated or divorced. Only one patient did not complete high school; 13% were high school graduates, one-third had some college or technical school education, 26.7% graduated from college with a bachelor's degree and 20% had a graduate level degree. For total annual household income, only 12 subjects

responded. Five subjects were in the range of \$10-50,000, while 7 fell in the brackets ranging from \$80,000 to over \$100,000.

Forty percent (n=6) of the population was “newly” diagnosed, within the past two years, one-third were diagnosed over ten years ago, and four patients were middle of the road, having been diagnosed anywhere from 3-8 years ago. Almost three-fourths of patients were on oral diabetes medications and one-third took insulin; one patient was on both oral medications and insulin, and another patient was not taking any form of diabetes medication. Sixty percent of the subjects had their hemoglobin A1c tested within the past three months, following the recommendation of the American Diabetes Association. Over a quarter were tested within the past six months, and one patient had not been tested ever, another was tested in the past two years. Of those patients tested, 9 had HbA1c values below 7.0, 20% had values between 7.0 and 8.0, one patient was above 8.0 and one did not remember what the result of their last test was.

### **Changes made to the initial pilot survey**

Based upon feedback given in both the online and in-person pilot tests, a few questions were altered and some new questions added. The newer version of the questionnaire was then taken by 4 subjects, two from each patient population. The next phase of the study, the pretest will be discussed.

### **Pretest response rates**

For the pretest phase, the survey was deployed Monday September 21, 2009 at 6:44pm and the last survey was taken Thursday September 24, 2009 at

11:59am before the survey was shut down at 100 respondents. For the pretest, there were 8 respondents who did not complete the survey. For the pretest phase, a 50/50 sample of users/non-users was desired, however, it became clear early on that 90% of the respondents were non-users. In the pretest population, only 13% of the population identified as members of online support groups. There were 8 women and 5 men, 9 identified as White, 3 were Black and 1 was Hispanic.

### **Pretest Results**

Descriptive statistics were performed on the pretest population on demographic characteristics such as age, gender, race/ethnicity, income, marital status and education. The population (n=100) had equivalent numbers of men and women, had a 19% minority population, had nearly equal representation of all age groups from 18-24 to over 65, and the majority of the population had some college education and or a college degree. Almost half of the population was married and had an annual total household income between \$10-49,000. The complete results of these analyses can be seen in table 3.5 below.

**Table 3.5: Demographic frequencies of the pretest population**

<b>Age (n=100)</b>	18-24	10 (10%)
	25-34	18 (18%)
	35-44	22 (22%)
	45-54	16 (16%)
	55-64	18 (18%)
	65+	16 (16%)
<b>Gender (n=100)</b>	Male	53(53%)
	Female	47(47%)
<b>Race/Ethnicity (n=100)</b>	Non-Hispanic White	81(81%)
	Non-Hispanic Black	14 (14%)
	Hispanic	3 (3%)
	Asian or Pacific Islander	2 (2%)
	Other	0
<b>Annual Household Income (n=100)</b>	<\$10,000	14 (14%)
	\$10,000 to \$49,999	46 (46%)
	\$50,000 to \$99,999	24 (24%)
	≥\$100,000	13 (13%)
<b>Marital Status (n=100)</b>	Never Married	27 (27%)
	Currently Married	46 (46%)
	Separated/Divorced	18 (18%)
	Widowed	9 (9%)
<b>Education (n=100)</b>	Some high school	6 (6%)
	High school graduate or GED	22 (22%)
	Some college or technical school	43 (43%)
	College graduate (bachelor's degree)	25 (25%)
	Graduate degree	8 (8%)

When we examine the diabetes-specific variables included in the survey, we see that 18% of the population was “newly” diagnosed, within the past two years, and an equivalent number of respondents were diagnosed over ten years ago. A majority of the respondents (n=32) were diagnosed anywhere from 3-5 years ago. An equal proportion of respondents fell in the 6-10 year range since date of

diagnosis. Three-fourths of patients (n=77) were on oral diabetes medications and 22% of respondents took insulin. One patient was not on any oral medications or insulin. Forty six percent of the subjects had their hemoglobin A1c tested within the past three months, following the recommendation of the American Diabetes Association. Over a quarter (n=31) were tested within the past six months, seven respondents had not been tested ever, and seventeen had been tested in the past two years. Of those patients tested, 8 had HbA1c values below 6.0, one third had values ranging between 6.0 and 7.0, 17% had values between 7.0 and 8.0, one patient was above 8.0 and 36 patients did not remember what the result of their last test was.

A few minor changes were made to the instrument prior to deploying in the main study group. Item 70 in the pretest (item 54 in the non-support group user survey), "What is (are) the reason(s) you would not join an online support group for type 2 diabetes?" (check all that apply), was altered to state, "What is the main reason you would not join an online support group for type 2 diabetes?" The response categories remained the same. The reason for this change was due to the high number of varied combinations in the responses and for reporting purposes. It was also decided that geographic information on respondents might be useful to have. An item that read, "In what region of the United States do you reside?", with the categories Northeast, Midwest, West and South and the respective states in parenthesis listed, was added. The results of this item and its relevance will be further discussed later on in Chapter 5.

For the support group users survey, the following item was added to assess the main motivating factor in joining an online group, and to allow the researcher to draw comparisons with the responses on item 54 that was mentioned above in the non-support group users survey. Item 53 asked respondents, "What is the main reason you joined an online support group for type 2 diabetes?". The responses included: "I felt that belonging to a group would benefit me", "I did not feel as though I had enough support from family and friends", "I did not feel as though I had enough support from my healthcare providers", "one of my health care providers recommended I join an online group", "someone else recommended I join an online group", "my interactions in a face-to-face support group led me to join an online group", "I wanted to meet other people with type 2 diabetes, and I needed help managing my type 2 diabetes".

### **Confirmatory Factor Analysis of Pretest**

Based upon initial confirmatory factor analysis, there were certain variables that were removed from the model because they either had very low factor loadings or did not measure the specified construct. In the original study model, illness identity was comprised of negative emotions, diabetes control beliefs, diabetes impact on relationships with others and friend and family support, while social identity included self-esteem, work-life balance, and diabetes impact on life in addition to traditional measures of social identity such as cognitive, affective and evaluative measures.



Confirmatory factor analysis revealed that diabetes control beliefs and relationships with others were not internally consistent and thus these variables were excluded from the model. The remaining seven constructs were tested in a confirmatory factor model and the fit was satisfactory. However, it was decided that the measures that would be retained to measure illness identity and social identity would be negative emotions and the three traditional measures of social identity. The other five constructs would be used in descriptive analyses and the results of those analyses can be viewed in Chapter 4. The fit of the confirmatory factor analysis model was very good. ( $\chi^2=90.44$   $df=69$   $p=0,04$   $RMSEA=0.035$ ) See Figure 3.4 for a depiction of the model and Table 3.6 for the standardized estimates and error variances of the model. Confirmatory factor analysis of the resulting study model can also be viewed in Chapter 4.

**Figure 3.4 :Confirmatory Factor Analysis of Proposed Illness and Social Identity Measures**

**Table 3.6 :Confirmatory Analysis of Proposed Illness and Social Identity Constructs**

<b>Indicator</b>	<b>Standardized Estimates (error variance)</b>
Nemo1	0.87 (0.24)
Nemo2	0.81 (0.34)
Ffsup1	0.82 (0.32)
Ffsup2	0.92 (0.15)
Si1	0.72 (0.49)
Si2	0.90 (0.19)
Si3	0.93 (0.14)
Se1	0.89 (0.20)
Se2	0.91 (0.18)
Dfut1	0.86 (0.27)
Dfut2	0.78 (0.39)
Dpres1	0.81 (0.34)
Dpres2	0.91 (0.18)
Wrklifbal1	0.99 (0.03)
Wrklifbal2	0.94 (0.12)

$X^2=90.50$   $df=69$   $p=0.042$ , Root mean square error of approximation (RMSEA)= 0.035, Non-normed fit index (NNFI)=0.99, Comparative fit index (CFI)=0.99, Root mean square residual (RMR)=0.039.

### Notes to Chapter 3

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## **CHAPTER 4**

### **RESULTS**

#### **Chapter Overview**

This chapter is organized into four sections with the results separated based on type of analyses and the testing of the study aims. The final study results will be discussed in the following order. In Section one, the study sample and the corresponding response rates will be described. Demographics of the study sample, results of the testing for non-response bias and results comparing the two different groups of respondents will also be discussed.

In section two, the descriptive results of all of the variables used in the study will be discussed in terms of mean scores. The correlations between the domains will also be shown. Beginning with the main construct of illness identity, diabetes beliefs regarding control, guilt and denial will be examined, as well as diabetes emotions, including hope, shame, envy, worry, anger, despair, and loneliness. Following that, the results related to the construct of social identity, as measured by diabetes' impact on life both present and future, one's social identification with diabetes, one's relationships with others and general self-esteem will be provided. Also discussed will be the construct of support group participation, defined by items related to frequency of use, types of activities,

types of interactions with other members, group self-esteem and cognitive, affective and evaluative identity with the support group. Finally, the results related to the constructs of goal setting, goal efficacy and goal achievement will be provided. These results will be discussed in terms of means and frequencies depending on whether the variable is continuous or categorical, respectively.

The third section will describe the performance of the various scales and items used in the survey via factor analysis and reliability analysis results. The final section will be devoted to the results of testing the study aims. Aim 1 was answered using structural equation modeling to test the main model of construct relationships in both the support group and non-support group population, aim 2 used mediated moderation analyses and aim 3 used moderated mediation analyses. To address aim 4, descriptive statistics, t-test, ANOVA and Pearson correlations were utilized.

### **Response Rate**

Due to the nature of online survey panels such as Zoomerang, calculating response rates is difficult. Zoomerang determines the number of panelists that receive an invitation to take the survey based upon the incidence of type 2 diabetics among the sample population and the number of completed surveys that the researcher requires. Information on response dates and times allows the researcher to track early responders and after a reminder email is sent, the late responders. The non-support group users survey was deployed Tuesday October 20, 2009 at 4:14pm and ended Thursday October 22, 2009 at 1:18 pm

after 166 respondents completed the survey. The support group user survey was launched October 21, 2009 at 4:55am.

It is unclear what the reasons are for non-response. Demographic information on non-responders is not available. Respondents were excluded from the study, and all three versions (the pretest, the non-users and the users) of the survey contained screen out questions. The main screening question was the item, "Are you a person with type 2 diabetes?". Respondents that answered "no" were not permitted to continue taking the survey and received the following message: Thank you for your willingness to participate, however, we are looking for survey respondents who fit a different profile. For the non-support group users survey, responding "Yes, I have participated in a support group online" to item 52 "Have you ever participated in any type of support group for type 2 diabetes?" Would also generate the same message and not permit the respondent to answer any further questions. Finally, respondents that did not fully complete the survey were not included in the final study sample.

The majority of survey questions were mandatory and would not allow the respondent to move on to the next question unless he or she provided a response. For this reason, in the pretest 8 respondents did not complete the survey. Responses to all survey items are available and can be seen in the Appendix. To increase the statistical power of both analyses, it was decided that the 100 pretest respondents would be included in the test groups. The tables below illustrate the demographics of both of the study populations with the inclusion of pretest responses.



## **Non-support group users**

For the test phase of the study, the sample of non-support group users (n=166) was 44% male (n=73) and 56% (n=93) female. The majority (61%) of the population was White (n=102). There were 39 Black (23%), 18 Hispanic (11%), and 5 Asian or Pacific islander (3%) respondents. Two respondents selected the “other” option and classified as White Hispanic and bi-racial, respectively. All age ranges were represented, however the majority of the population was over the age of 35. Eighteen percent (n=29) of the population were ages 18-34, 29% of the population (n=48) were ages 35-44, 21% of the population (n=35) were ages 45-54, 17% of the population (n=28) were ages 55-64 and 16% of the population (n=26) was over the age of 65. Exactly half of the population was married (n=83), thirty percent (n=49) never married, 17% were either separated or divorced, and seven respondents were widowed. The educational background of the respondents varied; two respondents did not complete high school, 16% were high school graduates, the majority (n=72) had some college or technical school education, 28% had completed a bachelor’s degree and 12% had a graduate level degree. For total annual household income 19 subjects were below \$10,000, 21% made between \$10,000 and \$29,000, 29% of subjects made between \$30,000 and \$49,000, 17% made between \$50,000 and \$69,000, 12% brought home between \$70,000 and \$99,000, and 11% of the population made over the \$100,000 annually.

With respect to diabetes history, nineteen percent of the population (n=32) were “newly” diagnosed, within the past two years, and the largest subset of

respondents (n=49) were patients diagnosed over ten years ago. The second largest subset (n=45), were diagnosed anywhere from 3-5 years ago. Sixteen percent of the population was diagnosed 6-8 years ago and eight percent received a diagnosis of diabetes 9-10 years ago. Three-fourths of patients (n=126) were on oral diabetes medications and 24% of respondents took insulin. There were no respondents in the sample that took both oral medications and insulin, nor were there any patients that did not take any form of medication. The majority of subjects (n=99, 60%) had their hemoglobin A1c tested within the past three months, following the recommendation of the American Diabetes Association. Twenty one percent were tested within the past six months, 7% were tested within the year and 9% within the past two years. Six respondents answered that he or she had not been tested ever. Of those patients tested, 15% (n=25) had HbA1c values below 6.0, one third had values ranging between 6.0 and 7.0, 14% had values between 7.0 and 8.0, eleven respondents had values above 8.0 and 44 (27% of population) patients did not remember the result of their last test.

**Table 4.1: Descriptive statistics of demographic information for Non-support group users**

<b>Age (n=253<sup>a</sup>)</b>	18-24	19 (7.5%)
	25-34	33 (13.0%)
	35-44	68(26.9%)
	45-54	50(19.8%)
	55-64	43 (17.0%)
	65+	40 (15.8%)
<b>Gender (n=253)</b>	Male	115 (45.5%)
	Female	138 (54.5%)
<b>Race/Ethnicity (n=253)</b>	Non-Hispanic White	174(68.8%)
	Non-Hispanic Black	49 (19.4%)
	Hispanic	20 (7.9%)
	Asian or Pacific Islander	7 (2.8%)
	Other	3 (1.2%)
<b>Annual Household Income (n=250<sup>b</sup>)</b>	<\$29,999	86 (34.4%)
	\$30,000 to \$49,999	65 (26.0%)
	\$50,000 to \$79,999	51 (20.4%)
	\$80,000 to \$99,999	17 (6.8%)
	≥\$100,000	31 (12.4%)
<b>Education (n=253<sup>c</sup>)</b>	Some high school	7 (2.8%)
	High school graduate or GED	46 (18.2%)
	Some college or technical school	108 (42.7%)
	College graduate (bachelor's degree)	66 (26.1%)
	Graduate degree	26 (10.3%)
<b>Geographic Residence (n=166)</b>	Northeast	32(12.6%)
	Midwest	40 (15.8%)
	West	39 (15.4%)
	South	55 (21.7%)

<sup>a</sup>n=253 reflects the inclusion of usable pretest respondents into the main study population.

<sup>b</sup>The question on annual income was not made mandatory and thus has missing responses.

<sup>c</sup>The question on geographic residence was not included on the pretest, resulting in a lower n value.

**Table 4.2: Descriptive statistics of demographic information for Support group users**

<b>Age (n=133<sup>a</sup>)</b>	18-24	3 (2.3%)
	25-34	13 (9.8%)
	35-44	23 (17.3%)
	45-54	41 (30.8%)
	55-64	28 (28.6%)
	65+	15 (11.3%)
<b>Gender (n=133)</b>	Male	45 (33.8%)
	Female	88 (66.2%)
<b>Race/Ethnicity (n=133)</b>	Non-Hispanic White	106 (79.7%)
	Non-Hispanic Black	9 (6.8%)
	Hispanic	5 (3.8%)
	Asian or Pacific Islander	5 (3.8%)
	Other	8 (6%)
<b>Annual Household Income (n=127<sup>b</sup>)</b>	<\$29,999	34 (23.5%)
	\$30,000 to \$49,999	32 (22.2%)
	\$50,000 to \$79,999	28 (19.5%)
	\$80,000 to \$99,999	15 (10.4%)
	≥\$100,000	18 (12.5%)
<b>Education (n=133)</b>	Some high school	6 (4.5%)
	High school graduate or GED	13 (9.8%)
	Some college or technical school	56 (42.1%)
	College graduate (bachelor's degree)	41 (30.8%)
	Graduate degree	17 (12.8%)
<b>Geographic Residence (n=122<sup>c</sup>)</b>	Northeast	23 (18.9%)
	Midwest	28 (23.0%)
	West	16 (13.1%)
	South	33 (27.0%)

<sup>a</sup>n=133 reflects the inclusion of usable pretest respondents into the main study population.

<sup>b</sup>The question on annual income was not made mandatory and thus has missing responses.

<sup>c</sup>The question on geographic residence was not included on the pretest, resulting in a lower n value.

## **Study variables**

The frequencies for all the variable responses in the study can be viewed in Appendix C. A selection of the notable responses will now be presented. Tables 4.3 and 4.4 include the responses provided for the emotion variables in the study for support group members and non-support group members respectively. The support group had higher ratings of envy, loneliness, anger, worry and despair. Ratings of hopefulness were nearly equivalent in both groups. When we look at the emotions related to denial, feelings that there is nothing wrong, that diabetes will be cured, or that diabetes will go away on its own, we see that non-support group members have slightly higher percentages of individuals stating that these statements describe them moderately to very well. For a complete listing of the number of responses for each response category and the corresponding percentage see Table 4.3 and 4.4 below.

**Table 4.3: Frequencies of Responses for Emotion Variables for Support Group Users**

<b>The following items ask how you feel about your diabetes on a number of issues. For each item, please tell us how strongly the item describes how you feel about having diabetes. On a scale of 1: doesn't describe me at all 3: describes me moderately well 5: describes me very well</b>					
	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
Top number is the count of respondents selecting the option. Bottom % is percent of the total respondents selecting the option.					
I believe that there is nothing wrong with me.	62 51%	20 16%	23 19%	13 11%	4 3%
I am certain that my diabetes will be cured.	53 43%	35 29%	24 20%	3 2%	7 6%
I feel hopeful despite my diabetes.	4 3%	15 12%	25 20%	39 32%	39 32%
I believe that my diabetes will go away by itself.	99 81%	16 13%	4 3%	2 2%	1 1%
I am embarrassed or ashamed about having diabetes.	79 65%	18 15%	14 11%	4 3%	7 6%
When I look at other people in good health, I get envious.	39 32%	24 20%	33 27%	17 14%	9 7%
I am worried about my diabetes.	8 7%	20 16%	43 35%	29 24%	22 18%
I am angry about my diabetes.	33 27%	27 22%	23 19%	26 21%	13 11%
I feel that nothing will ever be the same again.	35 29%	26 21%	28 23%	21 17%	12 10%
My diabetes makes me feel lonely at times, even when I am with others.	45 37%	25 20%	26 21%	14 11%	12 10%

**Table 4.4: Frequencies of Responses for Emotion Variables for Non-support Group Users**

The following items ask how you feel about your diabetes on a number of issues. For each item, please tell us how strongly the item describes how you feel about having diabetes. On a scale of 1: doesn't describe me at all 3: describes me moderately well 5: describes me very well					
Top number is the count of respondents selecting the option. Bottom % is percent of the total respondents selecting the option.	1	2	3	4	5
I believe that there is nothing wrong with me.	66 40%	37 22%	41 25%	13 8%	9 5%
I am certain that my diabetes will be cured.	39 23%	51 31%	45 27%	19 11%	12 7%
I feel hopeful despite my diabetes.	4 2%	10 6%	50 30%	56 34%	46 28%
I believe that my diabetes will go away by itself.	87 52%	41 25%	19 11%	9 5%	10 6%
I am embarrassed or ashamed about having diabetes.	106 64%	25 15%	15 9%	10 6%	10 6%
When I look at other people in good health, I get envious.	80 48%	25 15%	29 17%	16 10%	16 10%
I am worried about my diabetes.	21 13%	35 21%	57 34%	34 20%	19 11%
I am angry about my diabetes.	72 43%	34 20%	31 19%	17 10%	12 7%
I feel that nothing will ever be the same again.	75 45%	30 18%	33 20%	14 8%	14 8%
My diabetes makes me feel lonely at times, even when I am with others.	95 57%	25 15%	20 12%	12 7%	14 8%

With respect to wearing or carrying any form of diabetes identification, less than half (48%) of support group users responded yes, while only 28% of non-support group members responded yes. When we look at the provision of care, physicians provide all diabetes-related care to 34% of the non-support group population and 30% of the support group population. Pharmacists were rated as providing all diabetes related care in 5% of the non-support group population and 8% of the support group population. Endocrinologists provided all diabetes-related care to 11% of the non-support group and 13% of the support group population. These three providers provided the majority of care to the entire population when compared to nurses and physician assistants. Across both groups, around 60% of patients responded that their general family physician discussed goal setting to manage diabetes over the past three months.

With respect to goal setting, 11% of the non-support group population stated that monitoring blood glucose and conducting foot exams were not even goals that they had, as opposed to 4% and 5% respectively of support group respondents. Twelve percent of non-support group users stated that taking medication was not a goal, as did 7% of support group users.

Only 57% of non-support group users participated in diabetes education and similarly, only 61% of support group users also participated. The main reasons non-support group members stated for not joining any online support groups were a lack of interest in such groups (28%) and not having enough time (21%). For online support group members, 54% of respondents belonged to one group, 30% belonged to two groups and 19% had memberships in three or more



online groups. This question did not designate online **diabetes** groups, so the responses might indicate membership in groups for other conditions. With respect to participation frequency, 10% responded that they visited the group once, but never again, the largest proportion of the population (19%) visited 2-4 times a week and 20% (combined) visited the site at least once per day. The main reasons stated for joining an online group were feelings that belonging to a group would be beneficial (39%) and needing help managing diabetes (22%). Only 3 respondents stated that they did not have enough support from family and friends and 5 respondents stated that they did not have enough support from healthcare providers.

When we examine the frequencies of responses for the interactions within the support group we see that the majority of the support group population did not chat in real time, or post blogs or topics. However, the majority of the group did read others' blogs or topics and a good proportion of those individuals would respond to the blogs and topics they read. Nearly 80% of the support group population engaged in searches for information on both treatment and nutrition. It appears that half of the population had experience with goal setting and monitoring within the support group network. Complete support group interaction information can be seen below in Tables 4.5., 4.6, and 4.7.

**Table 4.5: Frequencies of support group interaction**

Item	Have never done this	Almost never	3	Moderately often	5	Very often
Participate in support forums and chat rooms	29 24%	30 25%	28 23%	19 16%	8 7%	8 7%
Read blogs or topics posted by others	8 7%	9 7%	29 24%	25 20%	28 23%	23 19%
Post my own blog or topic	60 49%	30 25%	17 14%	8 7%	4 3%	3 2%
Respond to blogs or topics posted by others	34 28%	27 22%	28 23%	21 17%	3 2%	9 7%
Search for diabetes-related information on treatment (medications)	7 6%	8 7%	14 11%	33 27%	30 25%	30 25%
Search for diabetes-related information on nutrition (diet tips, recipes)	4 3%	7 6%	17 14%	31 25%	27 22%	36 30%
Set a diabetes-related goal and monitor my progress toward goal	30 25%	18 15%	27 22%	21 17%	15 12%	11 9%

The psychological outcomes of the interactions, reading and searching that were described above in Table 4.5 can be seen in Table 4.6. Nearly 60% of support group members reported being able to see themselves in the experiences that other members post regularly, often or a lot. As a result, 75% of the population felt as though they were not alone in the struggle against diabetes. While only a small percentage (22%) felt as though they were role models or were looked upon to offer guidance or support, over 40% shared their illness experience with others in the group on a regular basis.

**Table 4.6: Frequencies of outcomes of support group interaction**

Item	This has never happened	Happens sometimes	Happens regularly	Happens often	Happens a lot
You see yourself in the experiences other members post.	12 10%	38 31%	32 26%	23 19%	17 14%
You feel as though you are not the only one.	9 7%	21 17%	37 30%	22 18%	33 27%
You are a role model to other members.	68 56%	27 22%	14 11%	6 5%	7 6%
You share your illness experience with other members.	38 31%	35 29%	18 15%	19 16%	12 10%
You are looked upon to offer guidance and support.	63 52%	32 26%	10 8%	10 8%	7 6%

The benefits of belonging to a support group and the interactions and actions one engages in within the group are detailed in Table 4.7. As reported earlier, the majority of the population engaged in searches for information about treatment and nutrition, and we see that nearly 90% of the support group population felt that the group provided them with useful diabetes-related information and advice. Over 60% of the population reported that the group helped them to set self-management goals, improved their confidence to achieve goals, and provided feedback to achieve goals. Nearly 75% of the group felt that belonging to a support group increased their acceptance of diabetes. See Table 4.7 for more results on other reported benefits.

**Table 4.7: Frequencies of benefits of support group interaction**

<b>Item</b>	<b>Not at all true</b>	<b>2</b>	<b>Moderately true</b>	<b>4</b>	<b>Very true</b>
Provided you with useful diabetes-related advice.	5 4%	9 7%	32 26%	27 22%	48 40%
Provided you with useful diabetes-related information.	6 5%	8 7%	28 23%	30 25%	49 40%
Helped you set goals to self-manage your diabetes.	15 12%	31 26%	28 23%	23 19%	23 19%
Improved your confidence to achieve diabetes-related goals.	12 10%	30 25%	27 22%	20 17%	32 26%
Increased your acceptance of diabetes.	14 12%	18 15%	30 25%	25 21%	34 28%
Provided feedback and encouragement on goal-related behavior.	26 21%	21 17%	28 23%	21 17%	25 21%
Made you feel better prepared for your next appointment with a healthcare provider.	24 20%	18 15%	27 22%	19 16%	32 27%
Improved your feelings of control over your diabetes.	13 11%	19 16%	32 27%	22 18%	33 28%
Increased feelings of self-worth.	26 22%	26 22%	31 26%	12 10%	25 21%

## **Non-support group Respondents versus Support group Respondents**

T-tests were used to explore any significant differences between groups on demographic information. The only significant differences were found for age  $t = -2.12$   $p = 0.035$ ; for gender  $t = -2.22$   $p = 0.027$  between the two groups. There were nearly twice as many female respondents in the support group study population, whereas in the non-support group study population there were equivalent numbers of men and women, which was a specification that was requested and provided by Zoomerang® in the recruitment phase. The mean age group for the support group study population was 45-54, for the non-support group study population, the mean age group was 35-44.

When we examine the differences between the two groups (support group participants and non-support group participants) with respect to diabetes clinical variables in the study, we see some significant differences. There were no significant differences between the two groups with respect to the amount of diabetes-specific care that certain health care providers (general physician, nurse or pharmacist) provide to the patient. However, there were significant differences with respect to the number of visits made to each health care provider (except for pharmacists), with the non-support group members visiting their general family physician twice in a three month period, compared to the support group members visiting the same provider only once on average in that same period. Non-support group members were also more likely to see other providers for diabetes care such as a physician assistant, nurse or endocrinologist. There were no

significant differences between the groups with respect to the number of times a pharmacist was seen.

When we look at HbA1c values and medication use in both populations, there are significant differences between the study subjects dependent upon whether he or she is more newly diagnosed (within the past 5 years) or has had diabetes for a longer period of time. In the support group study population, subjects that had received a diagnosis more than five years ago had lower mean HbA1c scores ( $t=2.25$ ,  $p=0.026$ ) than those that were considered more newly diagnosed. There were no significant differences between the more recently diagnosed and those diagnosed more than five years ago with respect to oral medication use, however, there were significant differences in insulin use, with patients diagnosed more than five years ago having higher rates of insulin use ( $t= -5.036$   $p<0.001$ ).

Comparing the support group population with the non-support group population in the study, it is found that those subjects in a support group are more likely to have HbA1c values at or below 7.0 ( $t=5.146$   $p<0.001$ ). The complete results of the tests for differences between the groups described above can be seen below in table 4.8.

**Table 4.8: t-tests for group differences on diabetes variables**

<b>Item</b>	<b>SG mean score ± SD</b>	<b>NSG mean score ± SD</b>	<b>t value</b>	<b>p value</b>
<b>Diabetes diagnosis</b>	2.45 ± 1.51	2.90 ± 1.47	2.77	0.006
<b>Last HbA1c</b>	1.58 ± 0.86	1.84 ± 1.16	2.26	0.024
<b>HbA1c test value</b>	2.40 ± 1.23	3.22 ± 1.59	5.15	0.000
<b>Oral Medication</b>	1.30 ± 0.46	1.20 ± 0.40	-2.13	0.034
<b>Insulin</b>	1.68 ± 0.47	1.78 ± 0.41	2.13	0.034
<b>Diabetes ID (jewelry, wallet card)</b>	1.55 ± 0.50	1.75 ± 0.43	4.03	0.000
<b>Diabetes Education</b>	1.41 ± 0.52	1.53 ± 0.56	2.04	0.042
<b>Relationship with Provider</b>	3.42 ± 1.65	2.91 ± 1.47	-3.09	0.002
<b># visits General Physician</b>	2.15 ± 0.88	3.78 ± 1.16	14.02	0.000
<b># visits Pharmacist</b>	2.53 ± 1.17	2.35 ± 1.30	-1.26	0.208

**Main survey measures: Differences in mean scores between the groups**

Scores of the respondent's diabetes control beliefs, perceptions of family and friend support, assistance with diabetes care, emotions regarding diabetes, relationships with others and the impact of diabetes on life, being able to maintain balance between work and life with diabetes, general self-esteem, identification with other diabetics and self-management goal behavior activities were constructed based on the methods described in the Chapter 3. Descriptive statistics for these variables are presented in the Appendix.

## **Diabetes Control and Friends and Family Support**

Significant differences related to control beliefs included two main beliefs. The first is that diabetes can be controlled by avoiding certain foods. The second belief is that diabetes can be controlled by taking medication. The mean score for the first belief was significantly higher (5.27, which corresponds to quite a bit on a scale from 1: not at all to 7: totally) for support group members than it was for non-support group members (mean score=4.96). For the second control belief an opposite trend emerged. Non-support group members had much higher scores (mean score=5.29) related to the belief that diabetes was controlled by medication than support group members (mean score=4.95). Both groups agreed that diabetes can be controlled by monitoring one's blood glucose levels regularly and by eating healthy and exercising. While it appears that there were no significant differences between the two groups with respect to acceptance and encouragement by family and friends with respect to diabetes and its management, the level of perceived comfort of family and friends with the individual's diabetes varied between the groups ( $t=3.26$   $p=.001$ ). Non support group members perceived a higher level of comfort (mean score 5.90, on a scale of 1-7) than did support group members (mean score 5.39). Refer to table 4.9 for the results of this analysis.



**Table 4.9: t-tests for group differences on diabetes control beliefs and friends and family support.**

Description of Measure <sup>a</sup>	SG n=133 Mean±SD	t value	p value	NSG n=253 Mean±SD
Diabetes is controlled by monitoring blood glucose	4.98 ± 1.49	-.133	.184	4.77 ± 1.43
Diabetes is controlled by eating healthy and exercising	5.21 ± 1.14	-.083	.410	5.11 ± 1.19
Diabetes is controlled by avoiding certain foods	5.27 ± 1.23	-2.27	.024*	4.96 ± 1.31
Diabetes is controlled by medication	4.95 ± 1.22	2.64	.009*	5.29 ± 1.18
Family and friends accept your diabetes and encourage you to manage it	5.36 ± 1.46	1.89	.060	5.64 ± 1.30
Family and friends are comfortable with your diabetes.	5.39 ± 1.51	3.26	.001*	5.90 ± 1.40

<sup>a</sup>Scale responses 1=not at all; 2=a very little bit; 3=somewhat; 4=moderately; 5=quite a bit; 6=very much; 7=totally.

### **Diabetes-related Emotions**

Emotions related to diabetes are mostly perceived to be negative, with hopefulness being one of the few positive emotions expressed by individuals with diabetes. In this study, negative emotions included envy/jealousy, loneliness, worry, anger and despair. The first two emotions were included as one variable in analyses and the other three comprised another variable. For both variables, support group members reported significantly higher levels of negative emotions (mean scores 2.43 and 2.85 respectively) than did non support group members (mean scores 2.09 and 2.48 respectively) While overall these scores all fall between the response categories 1: does not describe me at all to 3: describes me moderately well, it does appear that there are close to moderate levels of

worry, anger and despair in support group members. When we look at the positive emotion of hopefulness, we see that there is no difference between the two study groups, and both groups feel hopeful despite having diabetes (mean score for both groups 3.76 which corresponds to describes me moderately well on a scale from 1: does not describe me at all to 5: describes me very well).

**Table 4.10: t-tests for group differences on diabetes emotions**

Description of Measure <sup>a</sup>	SG n=133 Mean±SD	t value	p value	NSG n=253 Mean±SD
Envy and loneliness	2.43 ± 1.04	-2.82	.005	2.09 ± 1.17
Worry, anger, despair	2.85 ± 1.04	-3.35	.001	2.48 ± 1.05
Hopefulness	3.76 ± 1.11	-.005	.996	3.76 ± 1.00

<sup>a</sup>Scale responses 1=does not describe me at all; 3=describes me moderately well;

5=describes me very well

### **Diabetes Impact on Life**

Diabetes impact on life, as measured in this study refers to how having diabetes might change how one behaves or feels about himself in the present and in the future. Analyses (see Table 4.11 for values) revealed that there were significant differences between support group members and non support group members on the following impact on life variables: satisfaction with present abilities and life interference (t=2.68 p=.008), rearranging of life priorities and forming new friendships (t= -7.24 p=.000), and seeking a new meaning for life and making plans for the future (t= -4.13 p=.000). The first variable, which is related to satisfaction with present abilities and life interference, had greater relevance for non-support group members (mean score 3.86, on a scale of 1: does not describe me at all to 5: describes me very well) than support group members (mean score 3.59). The other two variables, which were considered to

be more future-oriented, had greater relevance for support group members (mean scores 3.24, 3.25 respectively) than non-support group members (mean scores 2.48, 2.82 respectively).

**Table 4.11: t-tests for group differences on diabetes impact on present and future life**

Description of Measure <sup>a</sup>	SG n=133 Mean±SD	t value	p value	NSG n=253 Mean±SD
I can do most things despite my diabetes <b>and</b> when I look in the mirror I see myself and not a person with diabetes	3.94 ± 1.10	1.74	.083	4.12 ± 0.88
Diabetes does not interfere with my life <b>and</b> I am satisfied with my present abilities despite having diabetes	3.59 ± 1.03	2.68	.008	3.86 ± 0.90
I am rearranging my life priorities <b>and</b> I am interested in forming new friends as a person with diabetes	3.24 ± 0.99	-7.24	.000	2.48 ± 0.99
I am seeking a new meaning for life <b>and</b> I accept help now that I am a person with diabetes	3.25 ± 1.01	-4.13	.000	2.82 ± 0.96

<sup>a</sup>Scale responses 1=does not describe me at all; 3=describes me moderately well;

5=describes me very well

### **Diabetes assistance and impact on relationships**

The impact that diabetes has on the individual was addressed in the above analyses, however diabetes can have an impact on the relationships that the individual has with others, particularly family, friends and healthcare providers. Often times, managing diabetes requires the assistance of these others. From Table 4.12 below, we see that both support group members and

non-members rely on their spouses/significant others, friends and other family, along with their healthcare providers moderately for assistance in managing their diabetes. Only a small proportion of the study population required assistance from a paid helper. The provision of assistance however did not seem to significantly impact the relationship between the subject and those caring for them, as the average rating for influence of care on relationships was “not at all”.

**Table 4.12: t-tests for group differences on assistance with diabetes care and impact of diabetes on relationships with others.**

Description of Measure <sup>a</sup>	SG n=133 Mean±SD	T value	p value	NSG n=253 Mean±SD
Assistance from spouse/significant other, other family and friends	3.61 ± 1.37	-0.43	.668	3.55 ± 1.34
Assistance from a paid helper	1.51 ± 1.15	.951	.342	1.64 ± 1.38
Assistance from a doctor, nurse and pharmacist	3.85 ± 1.36	.221	.825	3.88 ± 1.34
Impact on relationship with spouse/significant other	2.65 ± 1.22	-1.62	.107	2.44 ± 1.22
Impact on relationship with children	2.35 ± 1.37	-0.90	.367	2.21 ± 1.37
Impact on relationship with other family and friends	2.70 ± 1.33	-1.21	.226	2.53 ± 1.25

<sup>a</sup>Scale responses 1=does not apply; 2=not at all; 4=moderately; 6=considerably

## Social Identity

Individuals in support groups were more likely to have higher ratings of social identification with other diabetics. These individuals were more likely to see themselves as members of the group of all people with type 2 diabetes ( $t = -3.64$   $p = .000$ ), were more attached to this group ( $t = -4.55$ ,  $p = .000$ ) and had greater feelings of belongingness to the group ( $t = -3.50$   $p = .000$ ) than did subjects not in support groups. See Table 4.13 below for the mean scores and standard

deviations for each group. When we look at differences across groups and demographic variables, there were significant differences between Whites and minority study subjects. Minority (all Black, Hispanic, Asian/Pacific Islander and other) subjects had significantly higher ratings of social identity with the group of all persons with diabetes in the United States, particularly related to feelings of attachment and belongingness to the group ( $t=2.02$   $p=0.04$ ;  $t=2.18$   $p=0.03$ ). There were no differences between men and women, or the different age groups.

**Table 4.13: t-tests for group differences on social identity**

Description of Measure <sup>a</sup>	SG n=133 Mean±SD	t value	p value	NSG n=253 Mean±SD
Member of U.S. group of persons with diabetes	3.39 ± 1.24	-3.64	.000	2.91 ± 1.25
Attached to group of persons with diabetes	2.76 ± 1.23	-4.55	.000	2.17 ± 1.20
Belongingness to group of persons with diabetes	2.82 ± 1.26	-3.50	.001	2.36 ± 1.21

<sup>a</sup>Scale responses 1=not at all; 3=moderately; 5=considerably

### Self-esteem

General self-esteem was also measured in each group. There were no significant differences between the groups on ratings of self-esteem. Looking at the frequencies of results in both groups, 58% (n=96) of non-support group users gave ratings of 4 or 5 for personal satisfaction, as did 52% (n=62) of support group users. Ratings of 4 or 5 for positive attitude were given in 65% (n=107) of the population of non-support group users and 66% (n=78) of the population of support group users. Goal achievement self-esteem was also rated highly in the

majority (62% of non-support group users, 68% of support group users) of both groups.

**Table 4.14: t-tests for group differences on general self-esteem**

Description of Measure <sup>a</sup>	SG n=133 Mean±SD	t value	p value	NSG n=253 Mean±SD
Positive attitude toward self <b>and</b> able to achieve set goals	3.74 ± 1.03	-0.37	.713	3.70 ± 1.04
Satisfaction with self	3.44 ± 1.15	1.15	.253	3.59 ± 1.15

<sup>a</sup>Scale responses 1=strongly agree; 3=neither agree nor disagree; 5=strongly agree

### Work-life Balance

The eight items related to the impact of diabetes on one's ability to manage his or her personal and professional lives created a scale. All of the items were highly correlated, and so responses were divided randomly and then summed to create a score. Table 4.15 lists the measures that were included in each of the scores. Both groups had low scores, indicating that having diabetes did not keep them from maintaining a positive work-life balance.

**Table 4.15: t-tests for group differences on diabetes impact on work-life balance**

Description of Measure <sup>a</sup>	SG n=133 Mean±SD	t value	p value	NSG n=253 Mean±SD
Meeting work responsibilities/travel/good relationships/spending time with family & friends	1.83 ± 1.01	-1.33	.186	1.68 ± 1.06
Meeting household responsibilities/active/keeping a schedule/alone time	1.96 ± 1.04	-0.90	.370	1.86 ± 1.14

<sup>a</sup>Scale responses 1=not at all; 3= moderately; 5=considerably

## Goal Behavior

With respect to goal behavior, there appears to be significant differences between the groups on all lifestyle goals, but not medication goals. It appears that support group members have slightly higher ratings of goal setting for medication goals (4.31 versus 4.06 on a scale from 1: not a goal at all for me to 5: a strong goal for me) than non-support group members, although this finding was not large enough to be significant. There were however significant differences between the groups with respect to lifestyle goals ( $t = -4.80$   $p < 0.001$  and  $t = -2.92$   $p = 0.004$ ) with support group members having higher average ratings of goal strength when compared with non-support group members. See Table 4.16 for complete results.

**Table 4.16: t-tests for group differences on goal setting**

Description of Measure <sup>a</sup>	SG n=133 Mean±SD	t value	p value	NSG n=253 Mean±SD
Monitor blood glucose levels <b>and</b> avoid certain foods	4.11 ± 0.91	-4.80	.000	3.58 ± 1.10
Eat healthy <b>and</b> exercise <b>and</b> conduct foot exams	3.86 ± 0.86	-2.92	.004	3.56 ± 0.99
Take medication as prescribed	4.31 ± 1.81	-1.80	.074	4.06 ± 1.32

<sup>a</sup>Scale responses 1=not a goal at all for me; 3=moderate goal for me; 5=strong goal for me

Support group participants also rated their levels of confidence to self-monitor blood glucose levels and avoid certain foods higher than non-support group members. There were no significant differences in self-efficacy toward

taking medication, conducting foot exams, exercising or eating healthy between the two groups.

**Table 4.17: t-tests for group differences on goal self-efficacy**

Description of Measure <sup>a</sup>	SG n=133 Mean±SD	t value	p value	NSG n=253 Mean±SD
Confidence to monitor blood glucose levels <b>and</b> avoid certain foods	3.85 ± 0.91	-2.83	.005	3.56 ± 1.02
Confidence to eat healthy <b>and</b> exercise <b>and</b> conduct foot exams	3.53 ± 0.91	-1.46	.145	3.38 ± 0.97
Confidence to take medication as prescribed	4.27 ± 1.15	-1.63	.103	4.06 ± 1.24

<sup>a</sup>Scale responses 1=not at all confident; 3=moderately confident; 5=very confident

There were higher ratings of lifestyle goal achievement in the support group participants. For lifestyle goals related to self-monitoring blood glucose and avoiding certain foods, support group members had met this goal on average 3-4 days in the past week, while non-support group users had an average score of 1-2 days. For lifestyle goals related to exercising, eating healthy and conducting foot exams, both groups had average scores correlated to goal achievement 3-4 days in the past week, however the average was closer to 3-4 days for the support group study population and 61% of the population in this range.



**Table 4.18: t-tests for group differences on goal achievement**

<b>Description of Measure<sup>a</sup></b>	<b>SG n=133 Mean±SD</b>	<b>t value</b>	<b>p value</b>	<b>NSG n=253 Mean±SD</b>
Monitored blood glucose levels <b>and</b> avoided certain foods in the past week	4.37 ± 1.19	-4.30	.000	3.75 ± 1.44
Ate healthy <b>and</b> exercised <b>and</b> conducted foot exams in the past week	3.86 ± 1.01	-2.95	.003	3.49 ± 1.24
Took medication as prescribed in the past week	5.07 ± 1.71	-0.80	.423	4.92 ± 1.78

<sup>a</sup>Scale responses 1=not at goal of mine; 2=did not achieve this goal any day in the past week; 3=achieved this goal 1-2 days in the past week; 4=achieved this goal 3-4 days in the past week; 5=achieved this goal 5-6 days in the past week; 6=achieved this goal every day in the past week.

### **Evaluation of Measures**

The reliability and validity of measures for the constructs of health beliefs were evaluated. Because the main objective of the study was to examine the key relationships in the study model, the results of the evaluation of only those key constructs and the items that comprised them, which were included in both versions of the survey, are included here.

### **Cronbach's $\alpha$**

Cronbach's  $\alpha$  was used as the indicator for internal consistency for items that were grouped into what could be considered scales. In Table 4.19 the measures are listed, along with their corresponding alpha scores. As shown, all items except for two measures of family and friend support ( $\alpha=0.653, 0.672$ ), had values greater than 0.7, which were considered acceptable. (Nunnally 1994) In

addition, the deletion of a particular item did not improve the Cronbach's  $\alpha$  considerably, and thus all items in the table were retained.

**Table 4.19: Reliability of Survey Instruments.**

Measures	Item No.	Chronbach's $\alpha$	Item	$\alpha$ if item deleted
<b>Diabetes control beliefs</b>	<b>12-16</b>	<b>0.825</b>		
Monitor blood glucose			12	0.809
Eating healthy			13	0.749
Avoid certain foods			14	0.775
Physical exercise			15	0.778
Taking medication			16	0.833
<b>Support of family/friends</b>	<b>17-19</b>	<b>0.811</b>		
Level of acceptance of diabetes			17	0.672
Level of comfort with diabetes			18	0.653
Encourage diabetes management			19	0.898
<b>Assistance w/ care</b>	<b>20 a-h</b>	<b>0.771</b>		
<b>Diabetes emotions</b>	<b>2 h, m, j, k, l</b>	<b>0.846</b>		
Envy			2h	0.827
Loneliness			2m	0.804
Worry			2j	0.845
Anger			2k	0.795
Despair			2l	0.798
<b>Present impact on life</b>	<b>8-11</b>	<b>0.832</b>		
Satisfaction with abilities			8	0.828
Can do most things others can			9	0.780
Diabetes doesn't interfere in life			10	0.750
See myself, not person with diabetes			11	0.790
<b>Future impact on life</b>	<b>3-7</b>	<b>0.818</b>		
Rearranging life priorities			3	0.789
Seeking new life meaning			4	0.764
Accept help more			5	0.793
New friendships			6	0.788
Making future plans			7	0.776
<b>SI with other diabetics</b>	<b>27-29</b>	<b>0.892</b>		
Member of group of diabetics			27	0.911
Attached to group			28	0.819
Belongingness to group			29	0.801
<b>Relationships w/ non-patients</b>	<b>22a-h</b>	<b>0.848</b>		*all
<b>General self-esteem</b>	<b>30-32</b>	<b>0.904</b>		
Wholly satisfied with self			30	0.866
Positive attitude toward self			31	0.836
Able to achieve set goals			32	0.883
<b>Diabetes impact on work/life</b>	<b>24a-h</b>	<b>0.957</b>		*all $\alpha > 0.95$

## **Exploratory Factor Analysis**

An exploratory factor analysis was conducted first to identify the number of factors for each construct. Using the results of the exploratory factor analysis, a confirmatory factor analysis was conducted to examine the construct validity of the measures in the survey. A principle component factor analysis with promax rotation was conducted in SPSS v. 17.0 for all items included in Table 4.20, this table also includes the factor loadings, eigenvalues and percent of variance explained for each measures. Factor loadings for all variables were relatively high, with the exception of the item measuring medication taking goal setting, which had a loading of 0.284.

**Table 4.20: Item Loadings for Main model constructs**

<b>Item Number</b>	<b>Item Description</b>	<b>Factor &amp; Indicator #</b>	<b>Factor Loading</b>	<b>Eigenvalue</b>	<b>Percent of Variance Explained</b>
2h	Envy	Nemo1	0.670	3.10	62.05
2m	Lonely	Nemo1	0.772		
2j	Worry	Nemo2	0.582		
2k	Anger	Nemo2	0.800		
2l	Despair	Nemo2	0.796		
27	Membership	Si1	0.745	2.47	82.31
28	Attachment	Si2	0.898		
29	Belongingness	Si3	0.932		
39a	SMBG	Lsg1	0.640	3.15	52.49
39c	Avoid certain foods	Lsg1	0.860		
39b	Eat healthy	Lsg2	0.834		
39d	Exercise	Lsg2	0.639		
39e	Foot exam	Lsg2	0.587		
39f	Medication	Medg1	0.284		

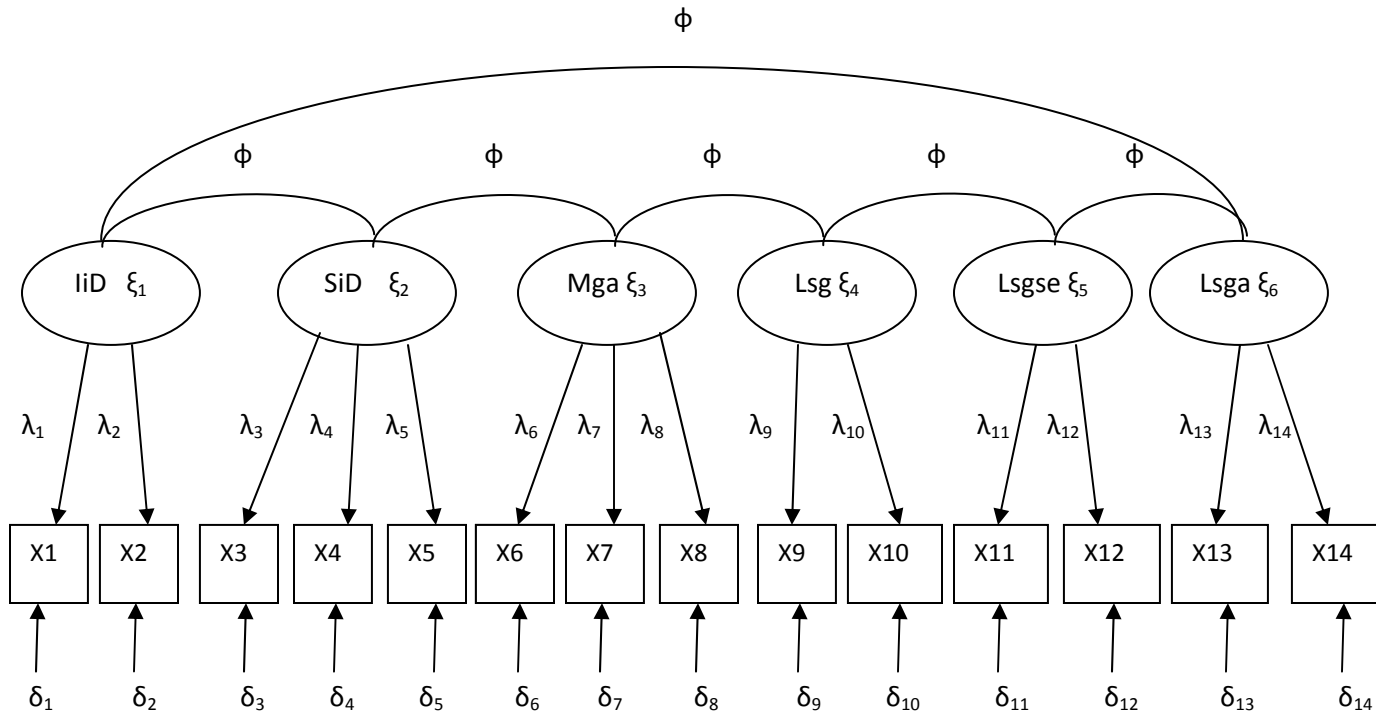
SMBG=self-monitoring blood glucose

## **Confirmatory Factor Analysis**

Structural equation modeling (SEM) techniques with LISREL version 8.80 software were used to conduct confirmatory factor analysis. The structure of the measures was examined and measurement models for the two main analysis groups were conducted. The confirmatory factor model that was tested can be seen in Figure 4.1.

Correlations for the non-support group main study model are presented in Table 4.21, the same correlations for the support group members are presented in Table 4.22. To assess the reliability and the validity of the measurement model we examined factor loadings (standardized estimates) and error variances and composite reliabilities. Composite reliability is calculated by dividing the factor loadings squared by the sum of the loadings squared plus the error variances. Similar to Cronbach's alpha coefficients, the values of composite reliabilities range from 0 to 1 and high values are favored. Results for this test are in Table 4.23 and 4.24.

Figure 4.1: Confirmatory Factor Model with Lisrel Notation



**Table 4.21: Non support group Main model Correlation Matrix**

	Si1	Si2	Si3	Lsg1	Lsg2	Medgb1	Lsgse1	Lsgse2	Medgb2	Lsga1	Lsga2	Medgb3	Nemo1	Nemo2
Si1	1.00													
Si2	0.648 <sup>a</sup>	1.00												
Si3	0.661 <sup>a</sup>	0.835 <sup>a</sup>	1.00											
Lsg1	0.179 <sup>a</sup>	0.246 <sup>a</sup>	0.209 <sup>a</sup>	1.00										
Lsg2	0.222 <sup>a</sup>	0.283 <sup>a</sup>	0.305 <sup>a</sup>	0.727 <sup>a</sup>	1.00									
Medgb1	0.006	0.031	0.035	0.328 <sup>a</sup>	0.263 <sup>a</sup>	1.00								
Lsgse1	0.099	0.175 <sup>a</sup>	0.105	0.684 <sup>a</sup>	0.579 <sup>a</sup>	0.270 <sup>a</sup>	1.00							
Lsgse2	0.153 <sup>b</sup>	0.228 <sup>a</sup>	0.198 <sup>a</sup>	0.531 <sup>a</sup>	0.711 <sup>a</sup>	0.196 <sup>a</sup>	0.798 <sup>a</sup>	1.00						
Medgb2	0.022	0.012	0.015	0.375 <sup>a</sup>	0.320 <sup>a</sup>	0.751 <sup>a</sup>	0.450 <sup>a</sup>	0.347 <sup>a</sup>	1.00					
Lsga1	0.112	0.148 <sup>b</sup>	0.110	0.642 <sup>a</sup>	0.442 <sup>a</sup>	0.231 <sup>a</sup>	0.624 <sup>a</sup>	0.498 <sup>a</sup>	0.327 <sup>a</sup>	1.00				
Lsga2	0.154 <sup>b</sup>	0.207 <sup>a</sup>	0.168 <sup>a</sup>	0.484 <sup>a</sup>	0.592 <sup>a</sup>	0.105	0.556 <sup>a</sup>	0.694 <sup>a</sup>	0.273 <sup>a</sup>	0.709 <sup>a</sup>	1.00			
Medgb3	-0.011	-0.001	-0.014	0.242 <sup>a</sup>	0.112	0.711 <sup>a</sup>	0.234 <sup>a</sup>	0.109	0.693 <sup>a</sup>	0.310 <sup>a</sup>	0.166 <sup>a</sup>	1.00		
Nemo1	0.216 <sup>a</sup>	0.336 <sup>a</sup>	0.349 <sup>a</sup>	-0.026	-0.039	-0.124 <sup>b</sup>	-0.156 <sup>b</sup>	-0.142 <sup>b</sup>	-0.192 <sup>a</sup>	-0.149	-0.110	-0.163 <sup>a</sup>	1.00	
Nemo2	0.245 <sup>a</sup>	0.332 <sup>a</sup>	0.332 <sup>a</sup>	0.033	0.013	-0.058	-0.218 <sup>a</sup>	-0.193 <sup>a</sup>	-0.156 <sup>b</sup>	-0.176 <sup>a</sup>	-0.112	-0.117	0.708 <sup>a</sup>	1.00

a=correlation significant at the 0.01 level b=correlation significant at the 0.05 level

Si=social identity ,Lsg1=lifestyle goals related to monitoring blood glucose and avoiding certain foods, Lsg2=lifestyle goals related to eating healthy, exercising, and conducting foot exams, Medgb1=medication goal setting behaviors, Lsgse1&2=lifestyle goal 1&2 self-efficacy, Mesgb2=medication goal self-efficacy, Lsga 1&2= lifestyle goal 1&2 achievement, Medgb3=medication goal achievement, nemo1=envy and loneliness, nemo2=worry, anger and despair.



**Table 4.22: Support Group Main model Correlation Matrix**

	Si1	Si2	Si3	Lsg1	Lsg2	Medgb1	Lsgse1	Lsgse2	Medgb2	Lsga1	Lsga2	Medgb3	Nemo1	Nemo2
Si1	1.00													
Si2	0.669 <sup>a</sup>	1.00												
Si3	0.728 <sup>a</sup>	0.825 <sup>a</sup>	1.00											
Lsg1	0.195 <sup>b</sup>	0.116	0.160	1.00										
Lsg2	0.142	0.047	0.177 <sup>b</sup>	0.679 <sup>a</sup>	1.00									
Medgb1	0.196 <sup>b</sup>	0.177 <sup>b</sup>	0.094	0.196 <sup>b</sup>	0.197 <sup>b</sup>	1.00								
Lsgse1	0.148	0.087	0.118	0.609 <sup>a</sup>	0.453 <sup>a</sup>	0.144	1.00							
Lsgse2	0.115	0.031	0.088	0.394 <sup>a</sup>	0.670 <sup>a</sup>	0.141	0.676 <sup>a</sup>	1.00						
Medgb2	0.148	0.160	0.128	0.181 <sup>b</sup>	0.175 <sup>b</sup>	0.808 <sup>a</sup>	0.266 <sup>a</sup>	0.208 <sup>b</sup>	1.00					
Lsga1	0.200 <sup>b</sup>	0.077	0.098	0.540 <sup>a</sup>	0.345 <sup>a</sup>	0.208 <sup>b</sup>	0.628 <sup>a</sup>	0.397 <sup>a</sup>	0.321 <sup>a</sup>	1.00				
Lsga2	0.071	-0.018	0.088	0.295 <sup>a</sup>	0.569 <sup>a</sup>	0.107	0.368 <sup>a</sup>	0.560 <sup>a</sup>	0.179 <sup>b</sup>	0.442 <sup>a</sup>	1.00			
Medgb3	0.152	0.026	0.062	0.117	0.210 <sup>b</sup>	0.771 <sup>a</sup>	0.128	0.169	0.698 <sup>a</sup>	0.226 <sup>a</sup>	0.172 <sup>b</sup>	1.00		
Nemo1	0.086	0.076	0.095	-0.049	-0.050	-0.165	-0.244 <sup>a</sup>	-.0148	-0.177 <sup>b</sup>	-0.207 <sup>b</sup>	-0.163	-0.107	1.00	
Nemo2	0.066	-0.024	-0.053	-0.124	-0.070	-0.085	-0.351 <sup>a</sup>	-0.236 <sup>a</sup>	-0.155	-0.233 <sup>a</sup>	-0.234 <sup>a</sup>	-0.072	0.637 <sup>a</sup>	1.00

a=correlation significant at the 0.01 level b=correlation significant at the 0.05 level

Si=social identity ,Lsg1=lifestyle goals related to monitoring blood glucose and avoiding certain foods, Lsg2=lifestyle goals related to eating healthy, exercising, and conducting foot exams, Medgb1=medication goal setting behaviors, Lsgse1&2=lifestyle goal 1&2 self-efficacy, Mesgb2=medication goal self-efficacy, Lsga 1&2= lifestyle goal 1&2 achievement, Medgb3=medication goal achievement, nemo1=envy and loneliness, nemo2=worry, anger and despair.

**Table 4.23: Confirmatory Analysis of the Main Study Model for Non-Support Group Users (n=253)**

Parameter	Estimate	Error Variances	Composite Reliability
$\lambda_1$	0.79	$\Theta\delta_1=0.38$	$\lambda_1 - \lambda_2 = 0.83$
$\lambda_2$	0.90	$\Theta\delta_2=0.20$	
$\lambda_3$	0.71	$\Theta\delta_3=0.49$	$\lambda_3 - \lambda_5 = 0.88$
$\lambda_4$	0.91	$\Theta\delta_4=0.17$	
$\lambda_5$	0.92	$\Theta\delta_5=0.16$	
$\lambda_6$	0.86	$\Theta\delta_6=0.25$	$\lambda_6 - \lambda_8 = 0.88$
$\lambda_7$	0.88	$\Theta\delta_7=0.23$	
$\lambda_8$	0.80	$\Theta\delta_8=0.36$	
$\lambda_9$	0.84	$\Theta\delta_9=0.29$	$\lambda_9 - \lambda_{10} = 0.84$
$\lambda_{10}$	0.87	$\Theta\delta_{10}=0.25$	
$\lambda_{11}$	0.89	$\Theta\delta_{11}=0.21$	$\lambda_{11} - \lambda_{12} = 0.89$
$\lambda_{12}$	0.90	$\Theta\delta_{12}=0.19$	
$\lambda_{13}$	0.81	$\Theta\delta_{13}=0.34$	$\lambda_{13} - \lambda_{14} = 0.83$
$\lambda_{14}$	0.87	$\Theta\delta_{14}=0.24$	

**$\chi^2=367.69$  df=62 p=0.00 RMSEA=0.14 NNFI=0.85 CFI=0.90 RMR=0.050**

**Table 4.24: Confirmatory Analysis of the Main Study Model for Support Group Users (n=133)**

Parameter	Estimate	Error Variances	Composite Reliability
$\lambda_1$	0.72	$\Theta\delta_1=0.48$	$\lambda_1 - \lambda_2 = 0.79$
$\lambda_2$	0.89	$\Theta\delta_2=0.22$	
$\lambda_3$	0.77	$\Theta\delta_3=0.41$	$\lambda_3 - \lambda_5 = 0.78$
$\lambda_4$	0.87	$\Theta\delta_4=0.24$	
$\lambda_5$	0.95	$\Theta\delta_5=0.10$	
$\lambda_6$	0.94	$\Theta\delta_6=0.12$	$\lambda_6 - \lambda_8 = 0.91$
$\lambda_7$	0.86	$\Theta\delta_7=0.26$	
$\lambda_8$	0.82	$\Theta\delta_8=0.33$	
$\lambda_9$	0.80	$\Theta\delta_9=0.37$	$\lambda_9 - \lambda_{10} = 0.72$
$\lambda_{10}$	0.85	$\Theta\delta_{10}=0.27$	
$\lambda_{11}$	0.84	$\Theta\delta_{11}=0.30$	$\lambda_{11} - \lambda_{12} = 0.81$
$\lambda_{12}$	0.81	$\Theta\delta_{12}=0.35$	
$\lambda_{13}$	0.69	$\Theta\delta_{13}=0.52$	$\lambda_{13} - \lambda_{14} = 0.61$
$\lambda_{14}$	0.64	$\Theta\delta_{14}=0.59$	

**$\chi^2=221.75$  df=62 p=0.00 RMSEA=0.14 NNFI=0.80 CFI=0.86 RMR=0.057**

For Aim 4 of the study, a confirmatory factor analysis was conducted on the proposed 11 constructs in the support group participation and identity model. The 11 constructs included support group benefits (both direct and indirect), interaction, search for information, support group relationship role, goal activity, outcomes of being in a support group, support group self-esteem, evaluative social identity, affective social identity and cognitive social identity. This model was an all x-model with 17 indicators. The model fit well ( $\chi^2=66.90$  (df=49)  $p=0.045$ ; RMSEA 0.045, NNFI=0.99, CFI=1.00 RMR=0.021) Table 4.25 displays the correlation matrix used in the analysis, with all significant correlations between the variables indicated. As this aim was analyzed more descriptively, a more complete analysis was not conducted.

**Table 4.25: Support group participation correlation matrix**

	Sgben 1	Sgben 2	lben1	lact1	lact2	lact3	Srch1	Srch2	Sgrole1	Sgrole 2	Gact	Sgout 1	Sgout 2	Sgse	Esi	Asi	Csi
Sgben1	1.00																
Sgben2	0.827 <sup>a</sup>	1.00															
lben1	0.529 <sup>a</sup>	0.375 <sup>a</sup>	1.00														
lact1	0.627 <sup>a</sup>	0.491 <sup>a</sup>	0.403 <sup>a</sup>	1.00													
lact2	0.533 <sup>a</sup>	0.508 <sup>a</sup>	0.101	0.516 <sup>a</sup>	1.00												
lact3	0.617 <sup>a</sup>	0.494 <sup>a</sup>	0.321 <sup>a</sup>	0.681 <sup>a</sup>	0.686 <sup>a</sup>	1.00											
Srch1	0.182 <sup>b</sup>	0.107	0.472 <sup>a</sup>	0.192 <sup>b</sup>	0.247 <sup>a</sup>	0.203 <sup>b</sup>	1.00										
Srch2	0.143	0.085	0.455 <sup>a</sup>	0.259 <sup>a</sup>	0.162	0.175 <sup>b</sup>	0.695 <sup>a</sup>	1.00									
Sgrole1	0.775 <sup>a</sup>	0.640 <sup>a</sup>	0.622 <sup>a</sup>	0.604 <sup>a</sup>	0.407 <sup>a</sup>	0.590 <sup>a</sup>	0.196 <sup>b</sup>	0.242 <sup>a</sup>	1.00								
Sgrole2	0.812 <sup>a</sup>	0.672 <sup>a</sup>	0.566 <sup>a</sup>	0.600 <sup>a</sup>	0.435 <sup>a</sup>	0.571 <sup>a</sup>	0.191 <sup>b</sup>	0.191 <sup>b</sup>	0.926 <sup>a</sup>	1.00							
Gact	0.330 <sup>a</sup>	0.297 <sup>a</sup>	0.317 <sup>a</sup>	0.261 <sup>a</sup>	0.356 <sup>a</sup>	0.236 <sup>a</sup>	0.245 <sup>a</sup>	0.316 <sup>a</sup>	0.344 <sup>a</sup>	0.360 <sup>a</sup>	1.00						
Sgout1	0.416 <sup>a</sup>	0.282 <sup>a</sup>	0.561 <sup>a</sup>	0.403 <sup>a</sup>	0.270 <sup>a</sup>	0.354 <sup>a</sup>	0.354 <sup>a</sup>	0.382 <sup>a</sup>	0.487 <sup>a</sup>	0.464 <sup>a</sup>	0.421 <sup>a</sup>	1.00					
Sgout2	0.416 <sup>a</sup>	0.289 <sup>a</sup>	0.592 <sup>a</sup>	0.455 <sup>a</sup>	0.276 <sup>a</sup>	0.389 <sup>a</sup>	0.390 <sup>a</sup>	0.421 <sup>a</sup>	0.503 <sup>a</sup>	0.481 <sup>a</sup>	0.430 <sup>a</sup>	0.938 <sup>a</sup>	1.00				
Sgse	0.600 <sup>a</sup>	0.536 <sup>a</sup>	0.530 <sup>a</sup>	0.551 <sup>a</sup>	0.459 <sup>a</sup>	0.521 <sup>a</sup>	0.296 <sup>a</sup>	0.272 <sup>a</sup>	0.590 <sup>a</sup>	0.602 <sup>a</sup>	0.380 <sup>a</sup>	0.697 <sup>a</sup>	0.709 <sup>a</sup>	1.00			
Esi	0.752 <sup>a</sup>	0.716 <sup>a</sup>	0.473 <sup>a</sup>	0.685 <sup>a</sup>	0.551 <sup>a</sup>	0.606 <sup>a</sup>	0.246 <sup>a</sup>	0.186 <sup>b</sup>	0.645 <sup>a</sup>	0.692 <sup>a</sup>	0.367 <sup>a</sup>	0.562 <sup>a</sup>	0.591 <sup>a</sup>	0.805 <sup>a</sup>	1.00		
Asi	0.716 <sup>a</sup>	0.679 <sup>a</sup>	0.538 <sup>a</sup>	0.663 <sup>a</sup>	0.514 <sup>a</sup>	0.548 <sup>a</sup>	0.274 <sup>a</sup>	0.289 <sup>a</sup>	0.628 <sup>a</sup>	0.655 <sup>a</sup>	0.361 <sup>a</sup>	0.591 <sup>a</sup>	0.620 <sup>a</sup>	0.845 <sup>a</sup>	0.888 <sup>a</sup>	1.00	
Csi	0.648 <sup>a</sup>	0.552 <sup>a</sup>	0.650 <sup>a</sup>	0.534 <sup>a</sup>	0.430 <sup>a</sup>	0.528 <sup>a</sup>	0.405 <sup>a</sup>	0.360 <sup>a</sup>	0.586 <sup>a</sup>	0.597 <sup>a</sup>	0.329 <sup>a</sup>	0.639 <sup>a</sup>	0.644 <sup>a</sup>	0.835 <sup>a</sup>	0.804 <sup>a</sup>	0.839 <sup>a</sup>	1.00

a=correlation significant at the 0.01 level b=correlation significant at the 0.05 level

## Structural Models

The structural models were tested in each study group and Tables 4.26 and 4.27 reveals the results of the parameter estimates. Theta-deltas ( $\theta_{\delta i}$ ) are the error variances of the independent and theta-epsilons ( $\theta_{\epsilon i}$ ) are the error variances of the dependent variables. Like the measurement model, all the lambdas were all high (above 0.70 for the non-support group model) except for  $\lambda_{y_9}$ . Most of the theta-deltas and the theta-epsilons were low to moderate, with the highest being 0.49 for the non-support group and 0.70 for the support group ( $\Theta_{\epsilon_9}=0.70$ ).

These results are indicative of convergent validity and the generalizability of the study measures. Results of the structural models show the effects of illness identity on social identity, goal setting, goal self-efficacy and goal achievement, as well as the effects of social identity on goal setting and goal self-efficacy. Model fit for both models will be discussed in the hypothesis testing section to follow.

**Table 4.26: Standardized Estimates of the Structural Model for Non-Support Group Users (n=253)**

Parameter	Estimate	Error Variances
$\lambda y_1$	0.72 <sup>a</sup>	$\Theta \epsilon_1=0.49$
$\lambda y_2$	0.91*	$\Theta \epsilon_2=0.17$
$\lambda y_3$	0.92*	$\Theta \epsilon_3=0.16$
$\lambda y_4$	0.87 <sup>a</sup>	$\Theta \epsilon_4=0.24$
$\lambda y_5$	0.81*	$\Theta \epsilon_5=0.32$
$\lambda y_6$	0.97 <sup>a</sup>	$\Theta \epsilon_6=0.07$
$\lambda y_7$	0.82*	$\Theta \epsilon_7=0.21$
$\lambda y_8$	0.90 <sup>a</sup>	$\Theta \epsilon_8=0.16$
$\lambda y_9$	0.78*	$\Theta \epsilon_9=0.41$
$\lambda y_{10}$	0.86 <sup>a</sup>	$\Theta \epsilon_{10}=0.26$
$\lambda y_{11}$	0.88*	$\Theta \epsilon_{11}=0.22$
$\lambda y_{12}$	0.80*	$\Theta \epsilon_{12}=0.36$
$\lambda x_1$	0.77 <sup>a</sup>	$\Theta \delta_1=0.41$
$\lambda x_2$	0.92*	$\Theta \delta_2=0.15$

<sup>a</sup>Parameter is fixed to 1.00. \*Significant level  $p < 0.05$

**Table 4.27: Standardized Estimates of the Structural Model for Non-Support Group Users (n=253)**

Parameter	Estimate	Error Variances
$\lambda y_1$	0.77 <sup>a</sup>	$\Theta \epsilon_1=0.41$
$\lambda y_2$	0.87*	$\Theta \epsilon_2=0.24$
$\lambda y_3$	0.95*	$\Theta \epsilon_3=0.10$
$\lambda y_4$	0.83 <sup>a</sup>	$\Theta \epsilon_4=0.29$
$\lambda y_5$	0.78*	$\Theta \epsilon_5=0.37$
$\lambda y_6$	0.94 <sup>a</sup>	$\Theta \epsilon_6=0.11$
$\lambda y_7$	0.73*	$\Theta \epsilon_7=0.32$
$\lambda y_8$	0.76 <sup>a</sup>	$\Theta \epsilon_8=0.42$
$\lambda y_9$	0.55*	$\Theta \epsilon_9=0.70$
$\lambda y_{10}$	0.93 <sup>a</sup>	$\Theta \epsilon_{10}=0.12$
$\lambda y_{11}$	0.86*	$\Theta \epsilon_{11}=0.26$
$\lambda y_{12}$	0.82*	$\Theta \epsilon_{12}=0.33$
$\lambda x_1$	0.71 <sup>a</sup>	$\Theta \delta_1=0.49$
$\lambda x_2$	0.90*	$\Theta \delta_2=0.20$

<sup>a</sup>Parameter is fixed to 1.00. \*Significant level  $p < 0.05$

## Hypothesis Testing

The study examined the relationships of illness identity and social identity, social identity and goal setting and goal setting and goal achievement. Structural equation modeling was conducted to test the strength and significance of these relationships and the overall fit of the hypothesized study model. For the potential moderating relationships in the study model, moderated mediation regression analyses were performed.

### Aim 1

**To determine the relationship between illness identity and social identity on goal setting and achievement in persons with type 2 diabetes.**

**Hypothesis 1.1:** For individuals with diabetes, illness identity influences one's social identity.

**Hypothesis 1.2:** The association between illness identity and social identity is greater in individuals that belong to an online diabetes support group than those that do not.

**Hypothesis 1.3:** Social identity influences both lifestyle and medication goals.

**Hypothesis 1.4:** Social identity is positively associated with an increase in goal self-efficacy.

**Hypothesis 1.5:** The relationship between goal setting and goal achievement is mediated by goal self-efficacy.

A depiction of the structural equation model, with the resulting path coefficients, for the support group member study population can be seen below in Figure 4.1. Paths that were significant are indicated.

## Figure 4.2: Structural Equation Model for Support group users

Structural equation modeling of the construct relationships displayed in figure 4.1 revealed that illness identity did not significantly influence social identity, however there was a significant path coefficient that was negative between illness identity and goal self-efficacy for lifestyle goals. The negative relationship between these constructs states that for support group members, as negative emotions (envy, loneliness, anger, worry and despair) regarding diabetes increase, goal self-efficacy decreases and vice versa. It was found that goal setting mediates the relationship between social identity and goal self-efficacy for lifestyle goals and that goal self-efficacy mediates the relationship



between goal setting and goal achievement. There was no support for the influence of social identity on medication goal activities. The model fit very well ( $\chi^2 = 86.86$  (df=59 p=0.011, RMSEA=0.054, NNFI=0.96, CFI=0.98, and RMR=0.047. See Table 4.28 for the standardized estimates of the betas and gammas for the study model and Table 4.29 for the variances of the study model variables.

**Table 4.28: Standardized Estimates for the Betas and Gammas of the Main Study Model for Support group Users (n=133)**

Parameter	Coefficients
$\gamma_{11}$	-0.01
$\gamma_{21}$	-0.15
$\gamma_{31}$	-0.43*
$\gamma_{41}$	-0.11
$\gamma_{51}$	-0.20*
$\beta_{21}$	0.21*
$\beta_{32}$	0.66*
$\beta_{43}$	0.55*
$\beta_{51}$	0.16

---

\*Significant path coefficients

**Table 4.29: Variances explained by the Main Study Model for Support group users (n=133)**

<b>Variable Name</b>	<b>R<sup>2</sup></b>	<b>R<sup>2</sup> for Construct</b>
Si1	0.59	0.00
Si2	0.76	
Si3	0.90	
Lsg1	0.70	0.06
Lsg2	0.62	
Lsgse1	0.89	0.49
Lsgse2	0.52	
Lsga1	0.58	0.53
Lsga2	0.30	
Medgb1	0.88	0.04
Medgb2	0.74	
Medgb3	0.67	
Nemo1	0.51	
Nemo2	0.80	

The test of the model resulted in a very good fit, and all of the hypothesized paths were significant at the .05 level.

### **Non-Support Group Users**

A depiction of the structural equation model, with the resulting path coefficients, for the non-support group member study population can be seen below in Figure 4.3. Paths that were significant are indicated.

### **Figure 4.3: Structural equation model for Non-support group users**

Structural equation modeling of the construct relationships displayed in figure 4.2 below revealed that illness identity did significantly influence social identity, and the more individuals identified with their illness, the more salient social identity was. There was also a significant path coefficient that was negative between illness identity and goal self-efficacy for lifestyle goals. The negative relationship between these constructs states that for non-support group members, as negative emotions (envy, loneliness, anger, worry and despair) regarding diabetes increase, goal self-efficacy decreases and vice versa. Illness

identity was also found to influence medication goal activities, and this was an inverse relationship as well. It was found that goal setting mediates the relationship between social identity and goal self-efficacy for lifestyle goals and that goal self-efficacy mediates the relationship between goal setting and goal achievement. There was no support for the influence of social identity on medication goal activities. This model also fit very well ( $X^2 = 135.13$  (df=59 p=0.00, RMSEA=0.068, NNFI=0.96, CFI=0.97 and RMR=0.053. See Table 4.30 for the standardized estimates of the betas and gammas for the study model and Table 4.31 for the variance explained by certain variables.

**Table 4.30: Standardized Estimates for the Betas and Gammas of the Main Study Model for Non-support group Users (n=253)**

Parameter	Coefficients
$\gamma_{1\ 1}$	<b>0.38*</b>
$\gamma_{2\ 1}$	<b>-0.15</b>
$\gamma_{3\ 1}$	<b>-0.33*</b>
$\gamma_{4\ 1}$	<b>-0.02</b>
$\gamma_{5\ 1}$	<b>-0.22*</b>
$\beta_{2\ 1}$	<b>0.45*</b>
$\beta_{3\ 2}$	<b>0.82*</b>
$\beta_{4\ 3}$	<b>0.66*</b>
$\beta_{5\ 1}$	<b>0.11</b>

---

\*Significant path coefficients

**Table 4.31: Variances explained by the Main Study Model for Non-support group users (n=253)**

Variable Name	R <sup>2</sup>	R <sup>2</sup> for Construct
Si1	0.51	0.16
Si2	0.83	
Si3	0.84	
Lsg1	0.76	0.11
Lsg2	0.68	
Lsgse1	0.94	0.60
Lsgse2	0.67	
Lsga1	0.84	0.51
Lsga2	0.59	
Medgb1	0.74	0.03
Medgb2	0.78	
Medgb3	0.64	
Nemo1	0.59	
Nemo1	0.85	

The percentage of the amount of variance that these variables explained were high, on average, except for the lifestyle goal achievement variables (eating healthy, exercising and conducting a foot exam) for support group members, which only explained 30% of the variance.

In order to cross-validate and compare the two main study groups in our cross-sectional analysis, multiple group analysis was conducted in SEM. The results of this analysis can be seen in Table 4.32. The results demonstrate that there were no significant differences among all model parameters across the two groups, except for gamma 1 1, which signifies the model parameter between illness identity and social identity. The chi-square difference test had a value above 3.84 and this was significant at p=0.002. The path coefficient was larger and

significant in the non-support group main structural model as well. Therefore we can conclude this effect is greater in the non-support group than in the support group.

**Table 4.32: Multiple Groups Analysis**

Parameter	Model $\chi^2$ value (df)	$\chi^2$ difference	p value
Lx, Ly invariant	221.99 (126)	3.27 (8)	0.916
$\gamma_{11}$	234.90 (127)	9.64	0.002
$\gamma_{31}$	225.72 (127)	0.46	0.498
$\gamma_{51}$	225.28 (127)	0.02	0.888
$\beta_{21}$	227.38 (127)	2.12	0.145
$\beta_{32}$	228.35 (127)	3.09	0.079
$\beta_{43}$	227.00 (127)	1.74	0.187
$\beta_{51}$	225.48 (127)	0.22	0.639

Baseline model  $\chi^2$  (118)=225.26;  $\chi^2$  difference is reported with 1 degree of freedom unless otherwise noted.

## Aim 2

**To determine the influence of support group identity on the relationship between social identity and goal setting in persons with type 2 diabetes.**

**Hypothesis 2.1:** The positive association between social identity and goal setting becomes stronger as the level of support group identity increases.

Aim 2 was tested using moderated mediation regression analysis as described in Chapter 3. The model that was tested can be seen in figure 4.3.

#### **Figure 4.4: Moderated mediation model for Aim 2**

The first test of the model looked at the moderating effects of support group identity (SGID) on the relationship between goal setting and goal achievement, which was hypothesized to be mediated by goal self-efficacy. The main result of this particular test was that the strength of lifestyle goals significantly predicts goal achievement. For lifestyle goals related to self-monitoring blood glucose (SMBG) and avoiding certain foods, there was a direct relationship between goal setting and goal achievement and this relationship was significant ( $t=2.68$   $p=0.008$ ). For these lifestyle goals, however, there were no moderated mediation

relationships between the variables. For the complete results of the regression see the following three tables listed under Table 4.33.

**Table 4.33: Moderated mediation regression results for Aim 2- Lifestyle goals related to SMBG and avoiding certain foods**

<b>Mediator Variable Model</b>				
<b>Predictor</b>	<b>B</b>	<b>SE</b>	<b>t</b>	<b>p</b>
Constant	3.362	0.567	5.929	0.000
SID	0.164	0.183	0.895	0.373
SGID	0.196	0.243	0.805	0.422
Inter1	-0.028	0.067	-0.421	0.674

\*SID=social identity SGID=support group identity Inter1=SID \* SGID

<b>Dependent Variable Model</b>				
<b>Predictor</b>	<b>B</b>	<b>SE</b>	<b>t</b>	<b>p</b>
Constant	1.120	1.120	0.999	0.319
SID	0.127	0.212	0.599	0.550
SGID	0.130	0.488	0.266	0.790
Inter1	-0.031	0.079	-0.394	0.694
LS goal setting	0.697	0.260	2.678	0.008
Inter2	-0.007	0.111	-0.061	0.952

\*SID=social identity SGID=support group identity Inter1=SID \* SGID Inter 2=lifestyle goal setting\* SGID



**Table 4.33: Moderated mediation regression results for Aim 2- Lifestyle goals related to SMBG and avoiding certain foods**

<b>Conditional Effects at specific SGID values</b>				
<b>SGID (W)</b>	<b><math>\hat{a}_1(b^{\wedge}_1 + b^{\wedge}_2W)</math></b>	<b>SE</b>	<b>z</b>	<b>p</b>
1.447	0.084	0.075	1.124	0.261
2.467	0.064	0.057	1.124	0.261
3.487	0.044	0.076	0.575	0.565

The second run of the moderated mediation analysis sought the same effects for goals related to eating healthy, exercising and conducting foot exams. This analysis also did not find any support for the main hypothesis of aim 2, however goal setting and goal achievement were also significantly related ( $t=3.35$   $p=0.001$ ) for these lifestyle goals. A complete listing of the results of this analysis can be seen below in the next three tables.

**Table 4.34: Moderated mediation regression results for Aim 2- Lifestyle goals related to eating healthy, exercising and conducting foot exams**

<b>Mediator Variable Model</b>				
<b>Predictor</b>	<b>B</b>	<b>SE</b>	<b>t</b>	<b>p</b>
Constant	3.627	0.538	6.742	0.000
SID	0.030	0.174	0.173	0.863
SGID	-0.009	0.231	-0.039	0.969
Inter1	0.019	0.064	0.312	0.756
<b>Dependent Variable Model</b>				
<b>Predictor</b>	<b>B</b>	<b>SE</b>	<b>t</b>	<b>p</b>
Constant	0.907	0.965	1.005	0.317
SID	0.076	0.173	0.439	0.662
SGID	0.095	0.405	0.235	0.814
Inter1	-0.015	0.064	-0.234	0.815
LS2 goal setting	0.773	0.231	3.350	0.001
Inter2	-0.046	0.095	-0.478	0.633

\*SID=social identity SGID=support group identity Inter1=SID \* SGID Inter 2=lifestyle goal setting \* SGID

<b>Conditional Effects at specific SGID values</b>				
<b>SGID (W)</b>	$\hat{a}_1(b^{\wedge}_1 + b^{\wedge}_2W)$	<b>SE</b>	<b>z</b>	<b>p</b>
1.447	0.042	0.072	0.581	0.561
2.467	0.052	0.052	1.010	0.312
3.487	0.061	0.066	0.925	0.355

The last and final step of this analysis was to test for moderated mediation in the relationship between support group identity and medication goal behaviors. While there was no support for the main hypotheses in medication goal behaviors, it was found that the setting medication goals and the subsequent strength of medication goals significantly predicts medication goal achievement ( $t=5.10$   $p<0.001$ ). See table 4.35 below for the complete results of the regression analysis.

**Table 4.35: Moderated mediation regression results for Aim 2- Medication goals**

<b>Mediator Variable Model</b>				
<b>Predictor</b>	<b>B</b>	<b>SE</b>	<b>t</b>	<b>p</b>
Constant	4.245	0.741	5.73	0.000
SID	0.113	0.239	0.469	0.639
SGID	-0.269	0.318	-0.845	0.399
Inter1	0.048	0.088	0.548	0.585

\*SID=social identity SGID=support group identity Inter1=SID \* SGID

<b>Dependent Variable Model</b>				
<b>Predictor</b>	<b>B</b>	<b>SE</b>	<b>t</b>	<b>p</b>
Constant	-0.193	1.007	-0.192	0.848
SID	0.187	0.234	0.799	0.426
SGID	0.230	0.385	0.598	0.550
Inter1	-0.091	0.088	-1.039	0.301
Medication goal setting	1.116	0.219	5.106	0.000
Inter2	0.004	0.082	0.047	0.962

\*SID=social identity SGID=support group identity Inter1=SID \* SGID Inter 2=medication taking goal setting \* SGID

<b>Conditional Effects at specific SGID values</b>				
<b>SGID (W)</b>	$\hat{a}_1(b^{\wedge}_1 + b^{\wedge}_2W)$	<b>SE</b>	<b>z</b>	<b>p</b>
1.447	0.204	0.156	1.308	0.191
2.467	0.261	0.121	2.149	0.032
3.488	0.317	0.163	1.943	0.052

Despite these findings, there was no support for the hypothesis. Support group identity does not influence the relationships between social identity and goal setting and goal setting on goal achievement.

### **Aim 3**

**To determine the influence of support group identity on the relationship between goal setting and goal achievement.**

**Hypothesis 3.1:** The positive association between goal setting and goal achievement becomes stronger as the level of support group identity increases.

**Hypothesis 3.2:** The level of support group identity increases patient's goal-related self-efficacy and thus strengthens the association between goal setting and goal achievement. As self-efficacy increases, goal achievement increases.

Aim 3 was tested using moderated mediation analysis. A depiction of the model tested can be seen in Figure 4.4. The results of this analysis found that for lifestyle goals related to monitoring blood glucose and avoiding certain foods, both support group identity ( $t=2.13$   $p=0.03$ ) and goal strength ( $t=4.95$   $p <0.001$ ) predict self-efficacy for that goal. See Table 4.29 for the complete results of the regression analysis.

**Figure 4.5: Moderated mediation model for Aim 3**

**Table 4.36: Moderated mediation regression results for Aim 3- Lifestyle goals related to SMBG and avoiding certain foods**

<b>Mediator Variable Model</b>				
<b>Predictor</b>	<b>B</b>	<b>SE</b>	<b>t</b>	<b>p</b>
Constant	-0.042	0.742	-0.057	0.955
LS goal setting	0.879	0.177	4.953	0.000
SGID	0.691	0.324	2.133	0.035
Inter1	-0.139	0.076	-1.828	0.069

\*SGID=support group identity Inter1=lifestyle goal setting \* SGID

<b>Dependent Variable Model</b>				
<b>Predictor</b>	<b>B</b>	<b>SE</b>	<b>t</b>	<b>p</b>
Constant	1.238	0.991	1.25	0.214
LS goal setting	0.087	0.315	0.274	0.784
SGID	-0.273	0.457	-0.596	0.552
Inter1	0.106	0.129	0.823	0.412
LS goal Self-efficacy	0.743	0.292	2.544	0.012
Inter2	-0.052	0.129	-0.401	0.685

\*SGID=support group identity Inter1=lifestyle goal setting \* SGID Inter 2=lifestyle goal self-efficacy \* SGID

<b>Conditional Effects at specific SGID values</b>				
<b>SGID (W)</b>	$\hat{a}_1(b^*_1 + b^*_2W)$	<b>SE</b>	<b>z</b>	<b>p</b>
1.447	0.453	0.113	4.024	0.000
2.467	0.330	0.081	4.083	0.000
3.487	0.222	0.112	1.982	0.0474

For lifestyle goals related to eating healthy, exercising and conducting foot exams, goal setting significantly predicts self-efficacy for the goal ( $t=4.89$   $p < 0.001$ ). See the following three tables for the complete results of the regression analysis.

**Table 4.37: Moderated mediation regression results for Aim 3-Lifestyle goals related to eating healthy, exercising and conducting foot exams**

<b>Mediator Variable Model</b>				
<b>Predictor</b>	<b>B</b>	<b>SE</b>	<b>t</b>	<b>p</b>
Constant	-0.018	0.740	-0.025	0.980
LS goal setting	0.899	0.184	4.887	0.000
SGID	0.381	0.308	1.235	0.219
Inter1	-0.090	0.075	-1.193	0.235

\*SGID=support group identity Inter1=lifestyle goal setting \* SGID

<b>Dependent Variable Model</b>				
<b>Predictor</b>	<b>B</b>	<b>SE</b>	<b>t</b>	<b>p</b>
Constant	0.926	0.885	1.047	0.297
LS goal setting	0.281	0.299	0.939	0.349
SGID	0.045	0.375	0.119	0.905
Inter1	0.062	0.118	0.523	0.602
LS goal Self-efficacy	0.604	0.264	2.287	0.024
Inter2	-0.112	0.108	-1.039	0.300

\*SGID=support group identity Inter1=lifestyle goal setting \* SGID Inter 2=lifestyle goal self-efficacy \* SGID



<b>Conditional Effects at specific SGID values</b>				
<b>SGID (W)</b>	<b><math>\hat{a}_1(b^{\wedge}_1 + b^{\wedge}_2W)</math></b>	<b>SE</b>	<b>z</b>	<b>p</b>
1.447	0.339	0.113	3.014	0.003
2.467	0.221	0.076	2.891	0.004
3.487	0.124	0.104	1.191	0.234

For medication goals, self-efficacy predicts achievement ( $t=2.72$   $p=0.007$ ) and the goal itself predicts self-efficacy ( $t=5.99$   $p< 0.001$ ). There is a significant interaction between self-efficacy and support group identity ( $t=-1.91$   $p=0.05$ ). The effect of the mediator, self-efficacy, on the dependent variable, goal achievement is dependent upon the moderator, support group identity. When support group identity scores are at least 2.46 (the mean), the effect of goal setting on achievement through self-efficacy is statistically significant ( $Z=2.09$   $p=0.04$ ). The following three tables present the complete results of aim 3 for medication goal behaviors

**Table 4.38: Moderated mediation regression results for Aim 3- Medication goals**

<b>Mediator Variable Model</b>				
<b>Predictor</b>	<b>B</b>	<b>SE</b>	<b>t</b>	<b>p</b>
Constant	0.774	0.575	1.345	0.181
Medication taking goal	0.776	0.129	5.99	0.000
SGID	0.048	0.212	0.224	0.823
Inter1	0.003	0.048	0.067	0.947

\*SGID=support group identity Inter1=medication taking goal \* SGID

<b>Dependent Variable Model</b>				
<b>Predictor</b>	<b>B</b>	<b>SE</b>	<b>t</b>	<b>p</b>
Constant	-0.979	1.010	-0.969	0.334
Medgoal1	0.514	0.314	1.639	0.103
SGID	0.397	0.384	1.028	0.306
Inter1	0.151	0.119	1.262	0.209
Mgse1	0.929	0.341	2.724	0.007
Inter2	-0.257	0.135	-1.911	0.053

\*SGID=support group identity Inter1=medication taking goal \* SGID Inter 2=medication taking self-efficacy \* SGID

<b>Conditional Effects at specific SGID values</b>				
<b>SGID (W)</b>	<b><math>\hat{a}_1(b^{\wedge}_1 + b^{\wedge}_2W)</math></b>	<b>SE</b>	<b>z</b>	<b>p</b>
1.447	0.435	0.147	2.951	0.003
2.467	0.231	0.111	2.09	0.036
3.488	0.026	0.165	0.157	0.876

For the significant moderated mediation relationships, additional analyses were conducted. Results of boot strapping for the significant moderated mediation relationship can be viewed in Table 4.38. While none of the bootstrap estimates are significant, the confidence intervals for the mean=2.46 do not contain zero and an indirect effect can be deemed different from zero if zero is not inside the upper and lower bounds. When we conduct the Sobel test ( $z = a \cdot b / \sqrt{b^2 \cdot s_a^2 + a^2 \cdot s_b^2}$ ) using the following values provided by the Modmed regression output,  $a = 0.7762$ ,  $S_a = 0.1295$ ,  $b = 0.9297$ ,  $S_b = 0.3413$ , we get the following results: Sobel test statistic= 2.4799 St. Error=0.2909  $p = 0.01$ .

**Table 4.39: Bootstrapping Estimates**

<b>SGID</b>	<b>Boot Ind.</b>	<b>Boot SE</b>	<b>Boot p</b>	<b>Confidence Interval</b>
1.45	0.598	1.44	0.150	.086, 1.52
2.46	0.342	0.139	0.138	-.135, -.649
3.48	0.120	0.371	0.325	-.412, 1.15

#### **Aim 4**

**To characterize the interactions that may occur within the support group network and use these findings to hypothesize relationships between these interactions and the benefits from such interactions on goal setting.**

Aim 4 was an exploration into the relationships of the variables that were measured, including support group interaction, support group benefits, support group role relationships, and support group outcomes. Support group frequency of participation and support group identity scores were utilized to make comparisons across the two groups. Tables 4.39 and 4.40 contain the complete results of the t tests for group differences.

**Table 4.40: Test of low versus high support group participation**

<b>Measures</b>	<b>Low Participation<sup>b</sup> N=51 Mean±SD</b>	<b>t value</b>	<b>p value</b>	<b>High Participation<sup>c</sup> N=80 Mean±SD</b>
Direct benefit of support group (sgben1) <sup>a</sup>	1.92 ± 1.12	-2.50	.014	2.43 ± 1.15
sgben2 <sup>a</sup>	1.82 ± 1.18	-0.65	.515	1.96 ± 1.20
Indirect benefit of support group (iben1) <sup>a</sup>	2.59 ± 1.02	-4.81	.000	3.49 ± 1.07
Type of interaction (iact1)	2.22 ± 1.31	-4.03	.000	3.22 ± 1.45
iact2	2.02 ± 1.41	-0.59	.555	2.16 ± 1.31
iact3	2.43 ± 1.53	-2.08	.040	2.98 ± 1.47
Information searching (srch1)	3.96 ± 1.41	-2.10	.037	4.49 ± 1.38
srch2	4.10 ± 1.25	-2.03	.045	4.59 ± 1.40
Role in support group (sgrole1) <sup>a</sup>	2.02 ± 1.04	-2.66	.009	2.61 ± 1.36
sgrole2 <sup>a</sup>	2.00 ± 0.95	-2.51	.013	2.50 ± 1.22
Goal activity (goalact)	2.82 ± 1.62	-1.63	.106	3.29 ± 1.57
Group self-esteem (sgse)	2.11 ± 0.98	-4.48	.000	2.95 ± 1.08
Group identity-cognitive	2.20 ± 0.88	-4.32	.000	2.93 ± 1.01
Group identity-affective	1.93 ± 0.98	-4.19	.000	2.73 ± 1.12
Group identity-evaluative	1.78 ± 0.91	-3.47	.001	2.43 ± 1.12
Outcomes of being in a group (sgout1)	2.75 ± 1.11	-4.10	.000	3.52 ± 1.02
sgout2	2.76 ± 1.07	-4.94	.000	3.68 ± 1.02

<sup>a</sup>Scale responses include 1: this has never happened; 2: happens sometimes; 3: happens regularly; 4: happens often; 5: happens a lot.

<sup>b</sup>Low participation is defined as falling between one visit only and 9-12 visits per year

<sup>c</sup>High participation denotes visiting 2-3 times a month to more than once a day.

**Table 4.41: Test of low versus high support group identity\***

Measure	Low identity Mean score $\pm$ SD	t value	P value	High Identity Mean score $\pm$ SD
Sgben1	1.65 $\pm$ 0.86	-7.18	<0.001	2.89 $\pm$ 1.13
Sbgen2	1.39 $\pm$ 0.76	-6.11	<0.001	2.51 $\pm$ 1.29
Iben1	2.61 $\pm$ 0.97	-6.50	<0.001	3.73 $\pm$ 0.99
Interact1	2.04 $\pm$ 1.01	-8.04	<0.001	3.73 $\pm$ 1.39
Interact2	1.70 $\pm$ 1.04	-3.87	<0.001	2.56 $\pm$ 1.49
Interact3	2.10 $\pm$ 1.81	-6.26	<0.001	3.54 $\pm$ 1.47
Search1	3.92 $\pm$ 1.43	-3.12	0.002	4.67 $\pm$ 1.28
Search2	4.10 $\pm$ 1.36	-2.67	0.008	4.71 $\pm$ 1.28
Sgrelrole1	1.74 $\pm$ 0.84	-6.99	<0.001	3.06 $\pm$ 1.31
Sgrelrole2	1.75 $\pm$ 0.79	-6.67	<0.001	2.90 $\pm$ 1.17
Goalact	2.66 $\pm$ 1.51	-3.71	<0.001	3.63 $\pm$ 1.53
Sgout1	2.60 $\pm$ 0.93	-8.28	<0.001	3.90 $\pm$ 0.87
Sgout2	2.69 $\pm$ 0.91	-8.42	<0.001	4.02 $\pm$ 0.90

\*Low identity is defined as at or below the group mean score of 2.46 for support group identity, high identity denotes scores above 2.46.

Sgben=support group benefits. Interact1=participate in chat rooms and support forums. Interact3=post my own blog or discussion topic. Asi1=attachment and belongingness to support group. Asi2=commitment to support group. Esi1=I am a valuable member and I am an involved member. Esi2=I am an important member. Sgse1=Self-worth from being a member and pride in support group.

### **Support group members**

As participation increases, the individual is more likely to share his or her illness experience with other members and to be looked upon to offer guidance and support. In addition, as participation is more frequent, the individual is more likely to see themselves in the experiences other members post and feelings of loneliness decrease. Individuals with higher support group participation scores are found to more actively participate in support forums and chat rooms and also respond to blogs or topics others post. Searching for both treatment and diet information also increases with level of participation. As participation increases,

the level of support one receives also increases. These individuals report a higher level of empathic responses, consolation, encouragement, reassurance, compliments received and confidences exchanged.

As identity scores (SGID) increase, there is a linear increase in scores for the all of the support group interaction variables in the confirmatory model: benefits of support group interaction, actively participating in the group by chatting online with other members, posting information or responding to others' posts, searching for information related to treatment and healthy eating and providing support and being on the receiving end of support from other members.

When support group interactions are viewed from a socio-demographic perspective, there are no significant differences between men and women and between any of the age groups for any of the interaction variables. There were some interesting findings regarding marital status and types of interactions. It appears as though married subjects were more likely to interact with others in chat rooms and forums and also to respond to others members blogs than those subjects that identified as being separated or divorced (Bonferroni multiple comparisons ANOVA mean difference of 1.20  $p=0.003$ ; mean difference of 1.19  $p=0.004$ ). Separated or divorced study subjects also had much lower ratings of affective social identity (belongingness, commitment and attachment) toward the group when compared to married subjects (mean difference of 0.76  $p=0.030$ ; mean difference of 0.83  $p=0.013$ ).

When support group interactions are examined along with HbA1c levels of subjects, many significant differences between two groups of subjects—those with HbA1c values below 6.0 and those with values above 8.0 appear. Table 4.41 describes the findings of multiple comparisons. Mean differences in scores and accompanying p values from ANOVA comparisons reveal that those subjects with tight control (HbA1c values below 6.0) of diabetes have higher scores of affective social identity (belongingness, commitment and attachment), evaluative social identity (feelings of being a valuable and important member and level of involvement), sharing illness experience with others and being looked upon to offer guidance and support, and interacting with others in chat rooms, forums and responding to other members postings.

**Table 4.42: Bonferroni Multiple Comparisons ANOVA between subjects with HbA1c values below 6.0 and above 8.0**

<b>Dependent variable</b>	<b>Mean difference</b>	<b>Significance level</b>
Sgben1	1.27	0.009
Interact1	1.95	<0.001
Interact3	1.37	0.032
Asi1	1.17	0.026
Asi2	1.33	0.006
Esi1	1.45	<0.001
Esi2	1.23	0.011
Sgse1	1.29	0.010

Sgben= support group benefits. Interact1=participate in chat rooms and support forums. Interact3=post my own blog or discussion topic. Asi1=attachment and belongingness to support group. Asi2=commitment to support group. Esi1=I am a valuable member and I am an involved member. Esi2=I am an important member. Sgse1=Self-worth from being a member and pride in support group.



## **CHAPTER 5**

### **DISCUSSION OF RESULTS**

#### **Chapter Overview**

In this chapter, the interpretation of the results and subsequent discussion about implications of the results will be provided. To facilitate this discussion, a brief overview of the study objectives will be presented, followed by the interpretation of the results of the testing of each objective.

#### **Introduction**

The present study contributes to a better understanding of the role of patient support groups in the self-management of type 2 diabetes. The concept of identity has often been used to understand goal behaviors in the workplace and has been slowly introduced into the healthcare environment to understand how individuals cope with chronic illness, although the influence of identity on goal behaviors has not been thoroughly assessed. Healthcare providers are in a unique position to implement theory-based interventions or strategies to improve patient reported outcomes. This research is based on Tajfel and Turner's Social identity theory. This theory examines how individuals identify with, and behave as part of, social groups. Within this theoretical framework, group

identification has been found to be positively related to improved effort and motivation of the individual to attain goals. The results of this study indicate that individuals with increased ratings of social identity and support group identity also had higher ratings of goal setting, goal self-efficacy and goal achievement for both lifestyle and medication goals.

The overall aim of this study was to determine the influence of identity with the illness and with other individuals with the same illness on diabetes self-management goal setting and goal achievement. Individuals in the study could identify with a specific online support group, or a more abstract collectivity of all individuals with type 2 diabetes in the United States.

## **Hypotheses**

Guided by the theory of social identity, several hypotheses are proposed to achieve the study aims.

**Aim 1: To determine the relationship between illness identity and social identity on goal setting and achievement in persons with type 2 diabetes.**

**Hypothesis 1.1:** For individuals with diabetes, illness identity influences one's social identity.

**Hypothesis 1.2:** The association between illness identity and social identity is greater in individuals that belong to an online diabetes support group than those that do not.

**Hypothesis 1.3:** Social identity influences both lifestyle and medication goals.

**Hypothesis 1.4:** Social identity is positively associated with an increase in goal self-efficacy.

**Hypothesis 1.5:** The relationship between goal setting and goal achievement is mediated by goal self-efficacy.

**Aim 2: To determine the influence of support group identity on the relationship between social identity and goal setting in persons with type 2 diabetes.**

**Hypothesis 2.1:** The positive association between social identity and goal setting becomes stronger as the level of support group identity increases.

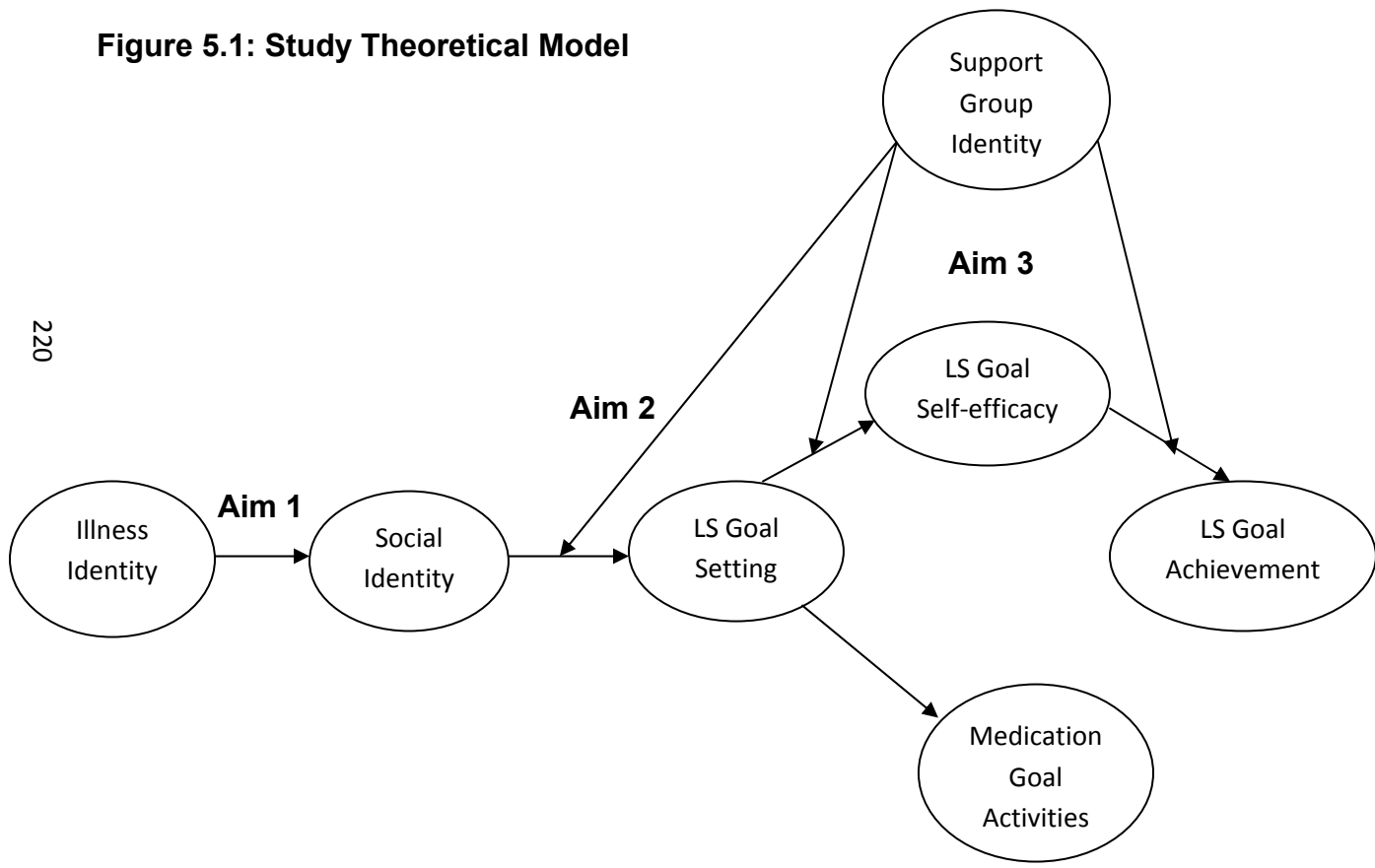
**Aim 3: To determine the influence of support group identity on the relationship between goal setting and goal achievement.**

**Hypothesis 3.1:** The positive association between goal setting and goal achievement becomes stronger as the level of support group identity increases.

**Hypothesis 3.2:** The level of support group identity increases patient's goal-related self-efficacy and thus strengthens the association between goal setting and goal achievement. As self-efficacy increases, goal achievement increases.

**Aim 4: To characterize the interactions that may occur within the support group network and use these findings to hypothesize relationships between these interactions and the benefits from such interactions on goal setting.**

**Figure 5.1: Study Theoretical Model**



## **Discussion of the Demographic Results**

When we look at the United States diabetes demographic statistics, we see that type 2 diabetes impacts men and women proportionately; there are over 12 million men with diabetes and 11.5 women with diabetes. In adult patients, 6.6% were non Hispanic White, 11.8% were non Hispanic Black, 10.4% were Hispanic, and 7.5% were Asian.<sup>1</sup>

The demographic characteristics of the participants completing both versions of the survey show that the majority of respondents in both populations (55% of non-support group users and 66% of support group users) were female (Tables 4.1 and 4.2). Our study sample had more females, which is not surprising because when we examine online support group participants, we see that there tend to be more women than men in such groups. Various studies on the use of online social networking and the use of online support groups report a range of results. In a study conducted by the Pew Research Center on Internet use, it was found that over 90 million individuals have participated in an online group of some form. When we examine the results of online support groups, the study reports that women tend to seek support for illness more so than men and are more likely than men to have more interactive relationships.<sup>2</sup> Such findings, with respect to participation and interaction, have also been observed within online social networking sites, such as Facebook® and LinkedIn®.<sup>3</sup> Another study found evident differences between genders with respect to types of interactions in online support groups; reporting that men tend to give and receive

information related to their condition, while women tend to give and receive encouragement and support.<sup>4</sup>

Eysenbach's study also found that men seem to be more attracted to virtual support groups than local support groups.<sup>4</sup> Because online groups allow the member to search for information to his questions, there is no investment of "face time" or embarrassment related to personal questions that one might experience in a face-to-face support group. In online groups there is no requirement to interact with other members and those that go to observe do not feel the pressure to participate that individuals in a face-to-face group might feel. Such groups aid in the collection of information to make rational health care decisions without having to form social relationships with others, something men might find appealing.

Other studies on self-help show that men are more likely than women to use self-help groups (i.e. Alcoholics Anonymous).<sup>5</sup> This study by Davions and colleagues included other support groups, including those for chronic illness, however the largest subset of the population was the substance abuse groups. Therefore the finding that men tend to participate more than women may be explained by the ways in which substance abuse is more stigmatized in women, resulting in fewer numbers of women participating in such groups. While the results of these various studies seem to be conflicting, there is an underlying implication for how such groups can attract and retain a male membership. Perhaps focusing on the chronic illness in the context of certain pastimes, might attract more male membership.

When we examine the types of interactions and role relationships that occur within this study population, we see that there really are no significant differences between men and women with respect to giving or receiving support, interacting with others, searching for information, goal setting, or perceived benefits and outcomes of support group membership. Additionally, men and women seemed to participate at equivalent rates as measured by the number of visits to the online support group within a specified time frame. Our findings suggest that both men and women in this particular study have the same level of need with respect to support and that belief was validated when the number one reason respondents listed for joining an online support group was “I felt that belonging to a group would benefit me”.

Some conditions and illness experiences are better suited for support groups than others. Diabetes, which is pretty prevalent, is an illness that may result in many different experiences that require support. Experiences such as diagnosis, the switch from lifestyle behavior modification to the use of oral medications, the switch from oral medications to insulin, complications resulting in nerve damage, limb amputation, blindness, kidney failure or cardiovascular disease, the loss of someone to diabetes or any other traumatic event that may or may not be related to diabetes but has an impact on how the individual copes and self-manages his or her condition.

Studies on self-help in the United States demonstrate that over a period of one year, 3-4% of the total population (25 million) participates in self-help. Caucasians are three times as likely as African Americans to participate, and

Hispanics participation rates fall in-between the two groups.<sup>5</sup> Within this study, our sample also consisted of a large proportion of Caucasians (nearly 70% in the non-support group population, and 80% in the support group population). While we were able to indicate the desired percentage of other minority populations such as African Americans and Hispanics for the non-support group user population within the Zoomerang® panel, this recruitment tactic was not feasible when recruiting from the online support groups. The small number of minorities in the support group phase might be indicative of a lack of minority representation in online support groups. It may also indicate that minority populations seek support groups that are more representative of their racial and ethnic background through other forums. Lastly, it may also signal a lack of willingness of minorities to participate in health research, as a result of unethical treatment of minorities in research trials such as the Tuskegee Institute's syphilis study. However, this phenomenon has been addressed in the literature and a meta-analysis of over 70,000 individuals across 20 studies found very small non-significant differences between non-Hispanic Whites and minorities with respect to willingness to participate in health research. Examining research enrollment decisions found that the focus for researchers should be increasing access and limiting barriers to participation and not changing minority attitudes concerning research involvement.<sup>6</sup>

Because recruitment within the different populations was not conducted proportionate to the distribution of the population in the United States, extrapolating the findings to a larger population might be difficult. While it was



not the primary objective of this study, it was hoped that the study population would somehow reflect the general population so that the results of this study would be somewhat generalizable to the population as a whole. Additionally, those individuals that did choose to participate in the study might have done so for many reasons. Interest in participating in research studies, interest in receiving compensation or interest in supporting the online group moderator's endorsement of the study may make this current study sample more of a convenience sample as opposed to being randomly recruited.

When we compare the two study groups, we found the only statistically significant differences were age and sex. Respondents in the support group were significantly older than respondents in the non-support group. Mean age range for non-support users was 35-44, while the mean age range for support group users was 45-54. The majority of the support group respondents were 45 and older (over 70%). A nationwide study of over 20 support groups for various conditions found that the average age of self-help participants was 43.1, which is somewhat younger than this study population.<sup>5</sup> Other studies<sup>7</sup> have shown that non-response rates increase with increasing age, however our study had 55 respondents age 65 and older, which signifies that use of an online survey did not necessarily exclude the elderly from participating.

Other assumptions that online survey populations, and online support group populations, might be younger, more educated and more affluent, were not substantiated in our study. The average household annual income of the respondents was between \$40,000 and \$60,000, in a range of below \$10,000 to

over \$100,000. In 2007, the US Census Bureau indicated that the median household income across all socioeconomic levels was \$50,233. The majority of the population had some college or technical school education, and the support group participants were slightly more educated. Again, looking at US Census Bureau data for 2004, we see that 85% of the population over the age of 25 (n=186, 877) had a high school degree and 27% had a bachelors degree or more. It is not clear what percentage of the US population had some college or technical school education. In Davison's cross-sectional study, the mean education was 12 years, or a high school degree for self-help participants, however not all groups included in the study were online support groups.

Prevalence by geographic region has been studied previously by Danaei and colleagues.<sup>8</sup> Using lab data from the National Health and Nutrition Examination Survey (2003-2006) and self-report data from the state-representative Behavioral Risk Factor Surveillance System (2003-2007), it was found that age standardized (in both groups of age 30-59 and  $\geq 60$ ) diabetes prevalence was highest in the Southern states of Mississippi, West Virginia, Louisiana, Texas, South Carolina, Alabama, and Georgia in both men and women. In the Northeastern state of Vermont, Minnesota in the Midwest and Montana and Colorado in the West had the lowest prevalence rates. Overall, the Southern and Appalachian states had the highest rates, while the Midwest and Northeast exhibited the lowest prevalence rates. Variation in these rates may be attributed to differences in risk factors such as obesity across the regions and also differential rates of diagnosis and treatment. In our study we had a higher

number of respondents from the South, suggesting that the number of respondents in both the Zoomerang® panel and within the various support groups might be more representative of Southern culture.

It was also found that after controlling for other factors, Hispanics had twice the odds of having undiagnosed diabetes when compared with Whites, which may explain the difficulty in recruiting such patients for the survey. Absolute prevalence as a percent of the total population was highest in the states where the Hispanic population is concentrated; New Mexico, Texas, Florida and California. When stratified by race, undiagnosed diabetes prevalence was greatest in Hispanics, followed by Whites and then Blacks. This finding can be attributed to socioeconomic disparities in the provision of health care services related to these individuals being underinsured or uninsured, therefore making detection of diabetes more difficult.

The results of the comparison between the two groups demonstrated some expected results. While both surveys were executed using online surveys, the Zoomerang® panel respondents consisted of individuals that self-selected to be members of the panel that agree to participate in online surveys for incentives. These individuals would need to be proficient in the use of email as this is the main form of communication from Zoomerang® to invite participants to take surveys. Likewise, respondents recruited from the online support groups would also be proficient in use of email. Both groups have access to computers as well as internet access.

The statistical differences reported above may be primarily due to the differences in sample size (n=253, n=133) and not entirely due to practically significant differences in mean differences in values. A comparison of other demographic characteristics supported the similarity of demographics between the two groups. Given the respondent information available there is no overt evidence of non-response bias.

### **Comparisons between the study groups on main study variables**

#### **Diabetes variables**

The largest category (40%) of support group users were newly diagnosed (within 0-2 years) and almost 60% of the population was diagnosed within the past 5 years. Newly diagnosed patients are also more likely to search for information and this search may lead them to an online support group. While it may be assumed that newly diagnosed patients are likely to require the most support, particularly related to lifestyle changes and new medication regimens required to manage diabetes, this may not be entirely true. This is evidenced by a lack of significant differences in support group participation and interactions between the more newly diagnosed (within the past 5 years) and those that were diagnosed over 5 years ago. This finding suggests that both types of patients have a similar experience within the group. It is also important to remember that at certain stages beyond diagnosis, the person with diabetes may require additional support. These stages include (but are not limited to) changes in oral

medication to insulin, amputation, blindness, loss of someone close that also has diabetes, and setbacks in glycemic control.

Control of HbA1c was greater in patients that received a diagnosis over five years ago and this finding could be an artifact of medication stabilization and the use of insulin, which was also reported to be higher in persons diagnosed over 5 years ago. Newly diagnosed patients are often initiated on oral diabetes medication and then insulin is added to the regimen when oral medication alone does not produce acceptable clinical ranges for HbA1c. It is also important to note that HbA1c levels can be relatively high at time of diagnosis, but tend to normalize to more acceptable levels when medication therapy is initiated.

Perhaps because non-support group members report more visits to health care providers, this significantly impacts the relationships they have with their health care providers. These individuals may be utilizing their interaction with the health care provider and the health encounter as a means of receiving support, thus scheduling more appointments. A 2X2 ANOVA reveals that support group members are also more likely to discuss setting goals with both their general family physician ( $F=24.96$ ,  $p<0.001$ ) and their pharmacist ( $F=3.96$ ,  $p=0.004$ ). If we use the discussion of goals as a proxy for strong communication between the patient and provider and this may explain the difference in the number of visits the support group member makes. We can also use HbA1c values as an indicator of the number of visits to a health care provider one might need to make. The more in control the patient is, the less often he or she might need to be seen by his or her health care provider.

## **Diabetes Control and Family and Friend Support**

Based on the t test for group differences displayed in Chapter 4, there are many significant differences between support group users and those that are not in a support group. These differences are with respect to certain diabetes control attitudes, the support of family and friends, negative emotions related to or as a result of being a person with diabetes, the impact that diabetes has on one's life (both present and future abilities), the strength of all lifestyle goals and related goal self-efficacy and achievement. In addition, there were highly significant differences between the groups in regards to social identification with other persons with diabetes, which one would expect to find.

The differences in control beliefs might be a result of a few factors. Support group members may have more access to information related to treatment and the influences of dietary changes on diabetes. For individuals in support groups, there are significant correlations between the belief that diabetes is controlled by avoiding foods and searching for diet tips and recipes in the support group forum (Pearson  $r=0.183$   $p < 0.05$ ) and also between the belief that diabetes can be controlled by medication and searching for treatment related information in the support group forum (Pearson  $r=0.210$   $p < 0.05$ ). Access to information, coupled with experiential advice and suggestions solicited and provided by other online group members regarding treatment success and failure may result in changes in the individual's beliefs about managing diabetes. Individuals that are not in support groups may only discuss treatment strategies with their health care provider and/or their families and thus only have the opinion

of one individual, or many conflicting opinions. A patient's locus of control may also play a role in which goals the patient sets. Lifestyle goals are goals that are made by the individual and the behavior is controlled by the individual. Medication taking is a behavior that is prescribed to the individual by her health care provider, and may or may not be a goal that is set participatively. Recommendations for care made by the provider may make the patient feel unable to exercise any control in their care.

Examination of the types of topics that are posted within the online community reveals that many members question the recommendations of their health care provider and seek confirmation or disconfirmation from other members, and the majority of these instances of doubt involve medication use. This observation might explain why control beliefs regarding lifestyle behaviors are greater than control beliefs regarding medication in this population. Another reason for preference of lifestyle goals by support group members might be related to the idea of a more holistic as opposed to biomedical approach to treating illness. Support group members may have different personalities than those that do not belong to support groups. Characteristics such as gregariousness, holistic, and participative might be used to describe such patients.

The level of perceived comfort of family and friends with the individual's diabetes varied between the groups ( $t=3.26$   $p=.001$ ). Non support group members perceived a higher level of comfort (mean score 5.90, on a scale of 1-7) than did support group members (mean score 5.39). This perception of

unease might be related to an individual's rationale to join a support group and seek the support and understanding of other individuals that have diabetes. However, only 3 respondents signified lack of support from family and friends as the primary reason for joining an online support group.

### **Goal behaviors**

With respect to goal behaviors in the study participants, there were significant differences found between the groups with respect to lifestyle goal strength and lifestyle goal achievement. Study participants in support groups had higher ratings of goal strength for all lifestyle goals (self-monitoring blood glucose, diet, exercise and foot exams) and also had higher levels of achievement for these goals. This may be attributed to several factors. The correlations between the responses support group participants provided for these goals and item 54g which asks the respondent how often he or she sets a diabetes-related goal and monitors goal progress in the online support group were examined. We found that for lifestyle goals related to self-monitoring blood glucose and avoiding certain foods, the correlation between goal strength and goal activity in the online support group is  $r=0.208$   $p<0.05$ . The correlation for goal self-efficacy of these goals and online goal activity is also significant at the  $p<0.05$  level.

For lifestyle goals related to exercising, eating healthy and conducting foot exams, the correlation between goal strength and online goal activity is  $r=0.320$   $p<0.01$ , and the correlation between goal self-efficacy and online goal activity is



also significant at the  $p=0.05$  level. Goal achievement and online goal activity is also significant at the  $p=0.05$  level for these goals. This finding suggests that using the tools available online to set and track goals in support groups can prove useful in achieving goal success. Although having the right tools does not necessarily mean that all individuals will participate in goal-setting. It may be said that certain individuals are more pre-disposed to setting goals, or are more goal-oriented. Another hypothesis is that the types of individuals that are attracted to online support groups are also the same individuals that are attracted to setting behavioral goals.

## **Study Aims**

### **Testing Aim 1**

Prior to discussing the actual relationships in the main study model that were significant and/or supported by the hypotheses, it is important to also discuss the lack of support for certain relationships between the constructs and the hypotheses that were not supported. These results were not interpreted as the overall structural equation model testing resulted in non-significant paths between the constructs.

There was no support for the hypothesis that illness identity influences social identity within the support group population of this study. We did however, find that illness identity was related to social identity for individuals not in a support group, whereby increased ratings of negative emotions related to diabetes result in greater identification with other persons with diabetes. This

relationship was direct and positive. This finding may suggest that individuals that experience heightened negative emotions have an illness identity that is more salient and thus might affect their social relationships with other. These individuals might relate more with other persons with diabetes. These individuals might also identify themselves as belonging to a larger group of persons with diabetes because being one of many is deemed better than being alone. To preserve self-esteem this mentality is adopted. The salience of social identity for these individuals might also be related to personal experience with the illness within their family and friends. This might also explain why these individuals do not need to join support groups. On the other hand, individuals who do not experience envy, loneliness, despair, and anger as a result of having diabetes seem to not identify as much with other persons with type 2 diabetes, meaning that perhaps illness identity is not a salient influence on the individual's social identity, therefore they do not identify with other persons with diabetes.

These findings are indicative of the measures that were used to define illness identity and social identity, and these measures are subjective. While there are validated measures of social identity that have been used in many different populations for many different behaviors<sup>9-11</sup> and these measures were adapted for use in this particular population, there are no traditional measures of illness identity. Many of the studies on illness identity (or illness conceptions or illness representations) are qualitative, either case studies or interviews with a small sample size and the results of these qualitative studies can be found in chapter 2. Using the results of such studies, measures related to emotions

toward having the illness were constructed along with other measures that might account for one's illness identity. However, confirmatory factor analysis revealed that emotions and diabetes impact on life were separate factors and thus not measuring the construct of illness identity. Emotions were retained as a proxy for illness identity and used to test the impact of such emotions on the other study constructs. Because social identity encompasses more than how the individual emotionally feels about having an illness, there was not a strong relationship between the two constructs in the model. While it was hypothesized that negative emotions might influence social identity, perhaps in the sense that if one felt negatively (isolated, envious of others in good health, angry, etc) about diabetes they would not want to associate herself with other persons with diabetes, there were no significant correlations among having negative emotions towards having diabetes and then feeling as though one was a member of a larger group of persons with type 2 diabetes in the United States.

The original study model had three separate constructs for medication taking. These constructs were goal strength (whether or not taking medication as prescribed was a strong goal for the individual), goal self-efficacy and goal achievement. Structural equation modeling of the model with these three separate constructs revealed that the path between social identity and medication goal setting (goal strength) was significant. However the paths between goal setting and goal self-efficacy and goal self-efficacy and goal achievement were not significant. Intuitively these findings do not make sense, given the population studied and the results found for lifestyle goals.

There are several reasons that might explain such results. First and foremost, there was only one measure for each of the three constructs, and the correlations among these measures were quite high and significant. The correlation between medication goal setting and medication goal self-efficacy was  $r=0.808$  with a  $p$  value less than 0.001. The correlation between medication goal setting and medication goal achievement was  $r=0.771$  and significant at the 0.001 level. The correlation between medication goal self-efficacy and medication goal achievement was  $r=0.698$  and also significant at the  $p<0.001$  level.

Due to the high level of correlation between these items, and the lack of significant paths between the constructs, the final study model combined these three measures into one item, as the measures seemed to be measuring the same construct. When a principle components factor analysis was conducted the factor loadings for medication goal setting, medication goal self-efficacy and medication goal achievement are 0.945, 0.855 and 0.816 respectively on one factor. When we combine the three measures into one factor, there was no significant path between social identity and medication taking activities for either group, however for non-support group users there was a significant path between illness identity and medication taking activities, which will be discussed later. DiMatteo conducted a meta-analysis of studies measuring medication adherence and found that many of the issues of such studies is the ways in which adherence is measured.<sup>12</sup> Single-item self-report measures of achieving medication-related goals are likely not the most effective means to measure adherence and should not be interpreted as such in this study.

Despite measurement error, other factors may contribute to non-significant findings related to medication use and identity in this population. There are many factors that contribute to medication non-adherence and these include lack of insurance, financial restrictions, patient-provider communication and relationship.<sup>12,13</sup>

The results of structural equation modeling did not find support for hypothesis 1. 1. Illness identity was not found to causally influence social identity, although for non-support group users, there were significant correlations at  $p < 0.001$  between both the negative emotion (nemo) indicators and all three of the social identity (si) indicators (See Table 4.16). This finding thus disconfirms hypothesis 1.2, which posited that the relationship between illness identity and social identity would be stronger in support group members. These findings are not entirely surprising given the fact that one's social identity can be comprised of many other factors besides negative emotions regarding one aspect (illness) of one's social identity. Many different group memberships can comprise one's social identity, such as race/ethnicity, gender, occupation, and these identities may be more salient than illness identity, thus making it difficult for the individual to place this identity in a group context. This may become even more difficult when there is not a readily available context such as an online support group. In this particular study, minorities across the two study groups however, were able to socially identify with a larger group of diabetics, but even for these subjects, there was no significant relationship between illness identity and social identity.

This finding is not surprising when we examine the clinical experiences with minority patients that the research team describes (per conversation with dissertation committee member Dr. Nancy Lewis). For minority patients, particularly Black patients, type 2 diabetes is a way of life. The prevalence in this population is such that nearly every individual has some personal experience with the illness and thus can more readily identify with it. It may be more easy for black individuals with diabetes to place themselves within the context of a larger group of individuals with the illness because within their traditional support structure of family and friends, they already belong to a larger group of persons with diabetes and thus feel a belongingness and attachment to such a group. There is also a difference between the races with respect to the discussion of illness. Minorities tend to take a more population-based approach to discussion and want to more openly discuss illness than do non-minorities, who tend to want privacy regarding such issues.

The study found support for hypothesis 1.3, in which social identity was found to influence lifestyle goals in both support group members and non-members. In initial SEM tests, social identity was found to be related to medication goal setting. However when the goal setting construct was parcelled with medication goal self-efficacy and medication goal achievement into one construct, this relationship became non-significant. Thus social identity did not have a significant influence on medication taking goals for either group. The reasons why social identity or group salience influence lifestyle goal behaviors and not medication taking behaviors are not obvious. Other studies<sup>14,15</sup> have

found that individuals that have high self-esteem, a component of social identity, are more likely to behave in ways that enhance this self-esteem. Behaviors such as healthy eating and exercise, as opposed to medication taking, may provide greater levels of self-esteem because they require more effort to achieve. There are positive associations between living a healthier lifestyle, weight reduction and improvement in self-esteem. Also, the act of taking medication, as described in other studies included in Chapter 2, is sometimes viewed as a failure, or an option of last resort when lifestyle changes are not effective. Therefore, patients might experience a decrease in self-efficacy when a particular medication they are on suddenly becomes ineffective or when they are switched from oral medications to insulin. In this particular study population, all subjects were on some form of medication. However, the attitudes the respondents had toward taking medication were not assessed beyond the beliefs that medication can control diabetes and medication is a goal the individual has. The responses to these questions might reflect a perceived (or real) expectation of the health care provider and not necessarily a strong personal goal that one sets.

For hypothesis 1.4, social identity did influence lifestyle goal self-efficacy, but indirectly through goal setting for both study groups. Intuitively this finding makes sense, as we would expect for goal self-efficacy to be dependent on the setting of a goal as well as goal strength. Additionally, for both study groups, illness identity was found (but not hypothesized) to have a negative inverse relationship with lifestyle goal self-efficacy. So for individuals with increased (decreased) negative emotions about having diabetes, there is a decrease

(increase) in the confidence level one has to achieve lifestyle goals. Anger, worry and despair can result in not only a decrease in confidence to achieve goals such as exercise and healthy eating, but can also result in harmful behaviors such as overeating or inability to engage in physical activity. Particularly for those individuals that had higher ratings of loneliness, this may be indicative of isolation. Isolating oneself is not conducive to executing some of the lifestyle goals in managing diabetes. Depression is a common co-morbidity of type 2 diabetes, and has been shown to negatively influence medication taking behaviors.<sup>16</sup> Individuals who did not feel negatively about their illness had higher ratings of confidence, and likely greater levels of self-esteem. These individuals were not lonely, did not feel envious of others and did not have elevated feelings of anger, worry or despair regarding their condition.

Self-esteem is another variable in these relationships. General self-esteem related to being able to achieve most goals one has set for himself was significantly correlated with goal self-efficacy for both sets of lifestyle goals ( $r=0.484$   $p=0.01$ ;  $r=0.498$   $p=0.01$ ). While there were no significant differences between the two study groups with respect to self-esteem ratings, there were differences between the groups with respect to goal setting, suggesting that self-esteem might not be the only contributing factor to goal setting. Other factors such as how one copes also may play a role in whether or not goals are set.

Finally, for hypothesis 1.5 lifestyle goal self-efficacy was found to significantly mediate the relationship between goal setting and achievement of all lifestyle goals. The relationship between goal setting and goal self-efficacy on



goal attainment has been studied in academic environments<sup>17,18</sup>, where self-efficacy beliefs both influenced goal setting and academic goal attainment. Applebaum and colleagues conducted a meta-analysis of self-efficacy as a mediator in the relationship between goal setting and achievement in the organizational environment finding that decreases in self-efficacy are associated with diminished motivation and performance.<sup>19</sup> Self-efficacy is the key in this relationship and strengthening self-efficacy beliefs is the focus of many organizations to aid in goal achievement. The findings of our study demonstrate that there is also a mediating relationship and that perhaps it is not enough to counsel patients on setting goals and setting them within the health care encounter. First we must assess the confidence of our patients to set and achieve goals and then construct strategies to improve self-efficacy beliefs in our patients.

## **Testing Aim 2**

Hypothesis 1.3 confirmed that there was a positive relationship between social identity and lifestyle goal setting. However, hypothesis 2.1 which posits that this association becomes stronger as the level of support group identity increases, was disconfirmed. The lack of support for support group identity influencing the relationship between social identity and goal setting suggests that there may be direct relationships between the variables (i.e. social identity on goal setting) and that the two identities do not interact to influence goal setting. Testing for direct relationships between social identity and support group identity is the next step for future research in this population.

There were not any significant findings for the role of support group identity on setting medication-related goals and this can reflect the types of support provided in online groups, an emphasis on controlling one's diabetes through factors other than medication, or the fact that members in online support groups may already be taking their medication and thus other behaviors such as exercising or monitoring blood glucose levels are more difficult to achieve. On certain sites, such as Daily Strength® and Diabetes Daily®, other members can provide feedback and encouragement for such goals and this may impact the level of confidence one has towards achieving the goal. An examination of the types of goals set on such sites reveals that the majority of goals involve weight loss through healthy eating and exercise, although some members include taking medications as a goal.

### **Testing Aim 3**

The main hypothesis of Aim 3 was that the positive association between goal setting and goal achievement would strengthen as the level of support group identity increased. Moderated mediation analysis did demonstrate that support group identity influenced the relationship of the mediator (goal self-efficacy) on the dependent variable (goal achievement) for medication goals. However there was no support for support group identity influencing the relationship between goal setting and goal self-efficacy for the same goals. In the previous analysis we also did not find any supportive evidence for this relationship between the constructs, and the potential reasons for such findings have already been stated. For lifestyle goals, there was no support for this hypothesis found in support

group members. The lack of support suggests that there is no interaction between support group identity and self-efficacy for lifestyle goals. The level of the moderator, support group identity scores might not influence self-efficacy in the sense that all individuals in the support group reported elevated levels of self-efficacy for such goals. This finding also corresponds to the diabetes control beliefs expressed by support group members that were greater for lifestyle behaviors. These individuals already report high levels of confidence to achieve lifestyle goals, and the reporting of confidence level was not in the context of the group's influence on self-efficacy. On the other hand, self-efficacy for certain individuals to achieve lifestyle goals is so low that support group identity has no incremental effect on improving confidence.

Support for the second hypothesis of Aim 3, which stated that the level of support group identity will increase patient's goal-related self-efficacy and thus strengthens the association between goal setting and goal achievement was found for medication goals. Support group identity did not influence the direct relationship between goal setting and goal achievement, but support group identity did interact with self-efficacy to increase goal achievement. We can interpret this finding in the following way: individuals in support groups already state that medication taking is a goal for them, and most of them conclude that it is a moderate to strong goal. Therefore identification with the group might not significantly influence goal setting, particularly for pre-existing goals. It may however, increase the levels of confidence one has to achieve the goal, particularly for individuals that have negative emotions regarding their illness or

their medication. Support groups provide access to educational information, experiential support and the advice and observations of other members interactions regarding the same issues the patient themselves might be experiencing with her medications. These tools can improve feelings of self-efficacy and promote goal achievement. So for individuals that already have medication goals in place, identity with the group can be a motivating force to increase confidence to achieve goals.

#### **Testing Aim 4**

When we look at the relationship between support group interaction and diabetes control, we found that those subjects with tight control (HbA1c values below 6.0) of diabetes have higher scores of affective social identity (belongingness, commitment and attachment), evaluative social identity (feelings of being a valuable and important member and level of involvement), sharing illness experience with others and being looked upon to offer guidance and support, and interacting with others in chat rooms, forums and responding to other members postings. It makes intuitive sense that individuals with better control of their diabetes would report better outcomes and have higher levels of identity. Particularly if the online support group played any part in the individual achieving goals and self-management behaviors, we would expect them to have an increased emotional and affective commitment to the group. Individuals that have HbA1c values below 6.0, and who report having achieved such control on their online support group profile page or within the forum would likely be viewed as the individuals other members would seek to offer guidance and support.

Within this study, individuals with HbA1c values at or below 7.0 reported greater levels of general self-esteem (personal satisfaction, positive attitude and confidence to achieve goals) than did individuals with HbA1c values above 7.0 ( $t = -3.00$   $p = 0.003$ ). Individuals with healthy self-esteem levels would feel more comfortable interacting with others in a chat room, sharing their illness experiences and responding to others questions or posts. As such, these individuals would also feel that their contributions to the group, as evidenced by posting valuable information or providing support to other members, as an indicator of their worth in the group. This sense of group worth is found in ratings of how valuable or important the member views himself as being to the group.

Aim 4 was an exploration into the mechanisms of an online support group. The main goal of this descriptive analysis was to determine if there are any differences within the group to generate hypotheses for future research. While we found strong evidence that support group identity significantly impacts the types of interactions, benefits and outcomes reported and the giving and receiving of support, the evidence was not so strong for support group participation. Therefore the relationship between participation in and identity with a support group needs to be further assessed. I would like to hypothesize that frequency of participation does not result in an increase in support group identity and that an increase in support group identity is derived from the benefits one receives through the interactions with other members in a supportive environment. There is a difference between the quantity of interaction and the

quality of interaction one experiences within the support group and this needs to be assessed.

This hypothesis leads to another possible test of the influence of identity within the support group. There are group processes underlying virtual communities and group norms that are expected to be upheld. Many individuals may choose to read and gather information and not participate because they are unsure of the norms dictating interaction or do not want to disturb the group process, or might fear that other members will not like or respect them. Others are more interactive and involved in group processes. Examining the differences between the more individualistic members and the more collectivist members of the group, as well as the influences of culture or ethnicity on group interactions is one possible extension of this study. Assessing group norms and the influence of a supportive normative environment on perceived behavioral control to execute self-management behaviors using the Theory of Planned Behavior (Ajzen) might also be a possible stream of research into online support group interactions. This theory assesses the influence of attitudes, subjective norms and perceived behavioral control on intentions to behave.<sup>20</sup>

Creating rival hypotheses is another means to examine support group interactions. An example of such would be that support from family can be important but does not interact with social identity or support group identity. This study did not assess the differences between traditional support networks (family and friends) and peer support per se.

Family support may be influenced by the fact that diabetes is hereditary. Therefore newly diagnosed patients may be familiar with certain aspects of diabetes, such as monitoring, dietary requirements and taking medications, because he or she has experienced another family member monitoring blood glucose or taking insulin. This familiarity can aid in the adoption of lifestyle behaviors and medication adherence, as well as provide the newly diagnosed patient with the peer support and confidence needed to achieve these behaviors. However, there can be disadvantages to exposure to diabetes provided from another family member and this involves the exposure of the complications of diabetes (e.g. amputations, heart attacks) which may result in depression and a sense of being doomed to experience the same complications. Individuals with these misconceptions don't often understand is that tremendous advances have been made in diabetes care since their parents or grandparents were diagnosed.

Another aspect of family support is that of support that lacks experience. Often times there is a sense of protectiveness and misguided support that others provide to the patient with diabetes because the family member is not entirely educated and/or feels that everything that has been learned can be applied to the family member that has diabetes. It is not uncommon to see this in parents of children with diabetes or spouses. Some patients with diabetes refer to the protectiveness and support as "policing"-a practice whereby other individuals monitor and regulate the behaviors of the person with diabetes. Usually this practice is seen with respect to diet, but can also include monitoring blood glucose, taking medications and exercising as well. While there were differences

between the two groups, and we may cautiously assume that non-support group members received adequate support from other sources, the study did not examine if one type of support can be more influential on self-management of diabetes. Another hypothesis for this type of study would be that peer support more significantly influences goal achievement than traditional non-peer support.

Diabetes is a disease that can be very individualistic in the sense that it can differentially impact different individuals based upon race, socioeconomic status, age and even gender. Illness severity, treatment strategies and comorbidities all contribute to a different experience for every patient. As such, using the experience of one patient to make assumptions about another with respect to treatment can be misinformed. That is why the information that is presented online and within online support groups must be carefully reviewed by a health care professional and moderated so that it is not misconstrued. Peer information, while having an experiential component that family support lacks, is often provided from the viewpoint of one individual and his or her experience. Without fully understanding how illness severity and comorbidities may play a role in determining treatment strategies, the individual may assert that because a particular treatment worked for them, it will work for others. The patient, then armed with this information, and perhaps more information (not always peer reviewed) gleaned from an additional search, begins to question the recommendations of his or her health care provider. This questioning can result in two different scenarios: in one, the patient consults his or her health care provider with the information and a dialog about the information can occur. Often



times, the health care provider may spend an inordinate amount of time explaining why the particular treatment would not be effective for the patient when compared to what the patient is currently taking/doing to manage his or her diabetes, and thus can be viewed as an inefficient use of time in the health care encounter. In the second scenario, there is no communication between the patient and the provider and the patient may opt to stop following the health care providers recommendations and thus becomes non-compliant. This non-compliance may result in a multitude of adverse events for the patient, further jeopardizing his or her health.

Finally, this study sought to measure the influence of identity and support on one outcome: lifestyle and medication goal achievement. Future research should determine if support group participants are able to achieve benefits beyond goal achievement, such as quality of life, improved health and improved identity. More investigation is needed to determine if online support is effective in assisting people to achieve such outcomes and how to create interventions that supplement traditional health care provision for chronically ill patients that use online support to improve outcomes.

## Notes to Chapter 5

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## **CHAPTER 6**

### **CONCLUSIONS**

#### **Chapter Overview**

This chapter is divided into four sections. The first section summarizes the results of the study aims. The second section describes the implications of the results. The third section explains the limitations of the study design and the biases that may have affected the study results. The final section of this chapter lists the directions for future research.

The aims of this research were to determine the relationship between identity and goal setting and goal achievement. The impact of support group identity on the relationship between social identity and goal setting and then goal setting and goal achievement as mediated by goal self-efficacy was also assessed. An exploration of the types of interactions and the outcomes of online interactions was also conducted. The study aims were tested by conducting an online survey in two different groups: those receiving online diabetes support and those that were not. A variety of statistical techniques were utilized to test the study aims.

Results obtained through different statistical tests were mostly consistent and the key finding of this study was that identity does play a crucial role in the goal process. The main findings of this research are summarized in the following section.

## **Summary of Study Aims**

### **Aim 1**

Aim 1 determined the relationship between illness identity and social identity. Illness identity was defined within this study as the negative emotions one might have in relation to having type 2 diabetes. Social identity referred to the identification with, and feelings of belongingness and attachment to the group of over 20 million people with type 2 diabetes in the United States.

Structural equation models were created to test the association between these two constructs on goal setting behaviors. Summarizing the SEM results, it could be concluded that within both support group users and non-support group users there was not a significant relationship between illness identity and social identity. However, social identity did significantly impact lifestyle goal setting for both groups. Social identity also influences lifestyle goal self-efficacy, as mediated by the strength of the lifestyle goal the individual had. The relationship between goal setting and goal achievement of lifestyle goals was also found to be significantly mediated by the level of confidence (self-efficacy) one had towards the goal. For both of the study groups, we also found that illness identity had a significant (but negative) relationship with lifestyle goal self-efficacy,

whereby higher ratings of negative emotions regarding diabetes were correlated with lower ratings of self-efficacy for lifestyle goals. From these findings we can conclude that social identity and illness identity both influence the goal setting process and that further studies are needed to determine if this link exists in other patient populations. Further refinement of the illness identity concept is needed, with measures that more accurately assess and completely capture how individuals define their identity within the context of illness.

In addition to these findings, we also found that for non-support group users there was a significant relationship between the illness identity construct and the medication goal activities construct. The medication activities construct included highly correlated measures of medication taking goal strength, confidence to take medications as prescribed and the achievement of this goal over the period of a week. As with the relationship between illness identity and lifestyle goal self-efficacy, this relationship was also negative, suggesting that higher ratings of negative emotions (anger, worry, despair, etc) result in a decrease in medication goal setting and goal strength.

Both models (the support and non-support group users) fit very well, although the model fit for the support group users ( $\chi^2=86.86$ ,  $df=59$ ,  $p=0.011$ ,  $RMSEA=0.054$ ,  $NNFI=0.96$ ,  $CFI=0.98$  and  $RMR=0.047$ ) was slightly better than the model fit for the non-support group users ( $\chi^2=135.13$ ,  $df=59$ ,  $p=$ ,  $RMSEA=0.068$ ,  $NNFI=0.96$ ,  $CFI=0.97$ ,  $RMR=0.053$ ) suggesting that the relationships between the constructs were more precise for support group users.

## **Aim 2**

Aim 2 tested the effect of the interaction between goal setting and social identity and social identity and support group identity on goal achievement. Aim 2 was tested using mediated moderation analyses in regression. The results of this test did not find that goal setting mediated the moderating effect of support group identity on the relationship of goal setting on goal achievement for the online support group participants. However, it was found that the strength of lifestyle and medication goals significantly predicts goal achievement. Gollwitzer however, suggests that the strength of the goal intention is not the only predictor of goal attainment<sup>1</sup>, despite the notion of most goal theories that states that setting the goal is the most important act of goal achievement.<sup>2-4</sup> Future research of the effects of social identity and support group identity should examine the effects of other factors in the goal attainment process such as implementation intentions (the plan to achieve a goal) and goal commitment (degree of determination to achieve a goal) to determine their role in goal achievement.

## **Aim 3**

Aim 3 examined the interaction of goal self-efficacy and support group identity and goal setting and support group identity on goal achievement. Using moderated mediation analysis, the moderating effect of support group identity on the mediating relationship of goal self-efficacy on goal setting and achievement a significant interaction between self-efficacy and support group identity was found. This finding implies that for online support group users, those that identify more

highly with their online support group have greater positive relationships between goal self-efficacy and goal achievement. Despite this finding, there was no significant moderated mediation effect of support group identity on the relationship between goal setting and goal self-efficacy. In addition to these findings, we see that support group identity and goal setting predict self-efficacy for goals related to self-monitoring of blood glucose levels and avoiding certain foods. For lifestyle goals related to healthy eating, exercising and conducting foot exams, and goal setting significantly predicted self-efficacy for the goal. For medication goals, self-efficacy is also found to significantly predict goal achievement. Medication goal setting is also found to significantly predict goal self-efficacy.

These findings imply that the support group identity has an important role in the goal process. Further studies are needed to determine the exact role of the support group in nurturing identity and fostering goal setting and achievement. In Chapter 5, we suggested that group norms and the role of a supportive normative environment in which others set goals and engage in self-management behaviors may be the key to promoting perceived behavioral control in the execution of goal behaviors.

#### **Aim 4**

Aim 4 was tested using descriptive statistics, ANOVA and t-tests to test for differences between low and high support group identity and low and high support group rates of participation. As discussed in Chapter 5, there are many



different ways in which the support group can influence patient care-by providing support to patients that need it: the newly diagnosed, the patient whose HbA1c needs better control, and the non-adherent patient. Even those patients who seemingly do not require high levels of support still engage in the group, either as mentors or as facilitators of group interactions. It is perhaps this role within the support group that keeps these patients in control of their illness.

### **Implications of the Results for Health Care Delivery**

The implications of this research on the provision of health care for patients with type 2 diabetes are two-fold. Results demonstrate that some patients identify more with their illness and with other persons with type 2 diabetes and this influences self-management of their illness. Future research involves assessing this identification within the health care encounter. This may address some of the barriers to goal setting and goal self-efficacy that can promote goal achievement and improve diabetes control. Second is determining if peer support is needed to eliminate the barriers discovered in step one, particularly when there is not an adequate level of support in the individual's traditional support network. Health care providers can provide information to the patient regarding the benefits of peer support and direct their patients to use such support. It would also behoove health care providers to investigate online support groups themselves. These groups and the access to information and the ability to witness the multitudes of interactions between members on such sites can help inform how the provider communicates with his or her patient. I believe that many health care providers are unsure about the role of peer support and

how this support can help them improve health-related outcomes for their patients. Educating health care providers about the benefits of support groups through studies such as this one is the first step.

An additional implication of the study's findings for health care delivery concerns goal behaviors. Some study respondents did not indicate that they set goals with the assistance of their health care provider. Although patients are capable of setting their own goals, doing so with a health care provider can improve the process and likely lead to better results. Being accountable to someone else can increase motivation and stave off barriers. Health care providers can increase goal self-efficacy by addressing patient-reported barriers and by directing patients to set realistic goals, something the patient may not be able to do on their own.

From a theoretical perspective, the study results do support the basic underpinnings of Social identity theory. This study examined how and why individuals identify with, and behave as part of, social groups. This group identification was found to be positively related to goal achievement and greater levels of confidence to achieve goals, perhaps on behalf of the group or because of the support of the group. Theories of goal setting were also supported by the key findings that goal setting improves goal achievement and that this relationship is mediated by goal self-efficacy.<sup>2</sup>

## **Implications of the results on the use of Social identity theory**

Utilizing social identity theory, as a basis for understanding the relationship between identity and behavior, this study found that there was a group effect on goal setting and goal achievement. The influence of social identification on goal setting and goal self-efficacy that was found in our study corresponds with what has been shown in the literature for organizational behavior. Our study examined identity in relation to categories or groups of individuals and then assessed if identity was formed by a self-categorization or identification with the two groups (all persons with diabetes in the United States and/or an online support group). The findings of our study suggest that there is a self-categorization process that occurs, resulting in feelings of attachment or belongingness to a larger societal group, or feelings of group self-esteem and identity (cognitive, evaluative and affective) with a smaller online community. It was found in our study that through interaction with others, an individual in a support group can gain certain attitudes, skills and self-efficacy to behave in certain ways, more specifically to set self-management goals. Social identity theory states that self-esteem and self-efficacy are processes that occur when identity is activated, and individuals in our study that had higher ratings of support group identity also reported increased general self-esteem, group self-esteem and confidence to achieve self-management goals. Feelings of confidence and a positive outlook is essential to not only set self-management goals, but to achieve them as well.

In Chapter 2, studies on support groups found that patients turn to support groups in stressful situations, when there is uncertainty about feelings, thoughts and behaviors. Many of our study respondents stated that they joined the support group to learn how to manage their condition. In order to reduce uncertainty these individuals communicated with others and searched for more information to reduce uncertainty.

The role of support groups in the identity formation process is in fostering the social comparison that occurs during the self-categorization process. This is also the motivational mechanism found in social identity theory. Social categorizations are based upon social comparisons. Social comparison principles state that in times of distress, individuals will compare themselves with others to evaluate their feelings and abilities. Individuals in this study reported that there were comparisons that took place, and these were positive comparisons that resulted in feelings of validation that they were not the only one and that others shared similar experiences with them. This comparison may have resulted in increased self-efficacy and greater motivation to continue self-improvement behaviors.

The theory of social identity was found to be an appropriate framework to assess goal behaviors in patients with type 2 diabetes. This finding has implications for the influence of identity within many other contexts of health behaviors and this theory needs further testing and perhaps refinement to assess its relationship to the cessation of aversive health behaviors, adherence to treatment recommendations and health care seeking behaviors.

## **Study Limitations**

Although this study does make several contributions, there are several constraints. These limitations and biases within the study must be taken into consideration, as they may have affected study results. There were some methodological limitations of the study. The mode of survey distribution (online self-administered) prohibits individuals that are illiterate or do not have access to computers. While access to computers has increased through public libraries and health care centers, using public computers to participate in research or to interact in online support groups about private matters related to one's health might not occur, thus limiting the outreach of the survey in more indigent populations.

To truly compare the differences between the groups included in the study, the same survey instrument should be administered to the entire population, despite limiting the extent to which certain groups (i.e. those not involved in a support group) were able to complete the questionnaire. The use of online support group participants did not permit access to medical charts and records to verify medication adherence and HbA1c self-report information provided by the patient. The accuracy of such measures has been examined extensively in the literature and is a limitation of this study. Other threats to internal validity in this study may be related to attrition of respondents. There was no guarantee that respondents would complete the entire survey, and the length and the method of delivering the survey are two weaknesses that resulted in many incomplete survey responses.

Recruitment practices for both study groups were not consistent and this may have influenced the types of respondents that comprised the final groups. The recruitment practice for the support group population was a convenience sample which was not randomly selected or sampled for demographic representation.

The patient population was selected by convenience sampling, rather than by random sampling of the population. In particular, patients that were selected from the diabetes ambulatory care clinic were asked to participate following an encounter with a pharmacist. It is unclear if these patients have different characteristics that would make the results of the study not generalizable to a larger population. In the pretest and main study test, individuals were recruited online through either an online respondent panel or from an online support group. Respondents selected from Zoomerang® to participate were selected at random from those that were profiled as having type 2 diabetes. Unfortunately, the respondents recruited from the various online support groups were not randomized, nor were the online groups selected to participate randomized in any way. It would be somewhat difficult to randomize members within an online group, however, future studies could be conducted using a randomization technique that would have the researcher randomly select members to participate and then forward an invitation to participate via a message, as opposed to posting an open discussion thread regarding the study with a link to the survey for all members to access. Additionally, the researcher could select at random, the online groups to sample from a pool of all online support groups. In

addressing this particular limitation of the study, we might make the results of the study more generalizable to the population of persons with type 2 diabetes in online support groups. However, as research within this population, particularly quantitative studies, is relatively novel, there are no published standards of recruitment protocol that could be used.

The \$10 incentive to participate in the study may have created a bias by attracting participants with financial need or with an interest in furthering research on type 2 diabetes, as the incentive could be donated to the American Diabetes Association. Those online members that did opt to participate in the study may also have a propensity for research and thus a self-selection bias exists. However, the incentive might also have been perceived as inadequate given the amount of time required to take the survey (20 minutes was the estimate given) and also given the personal nature of the subject matter. This may be one of the reasons for attrition of respondents.

Both versions of the instrument were quite lengthy; the non-support group member survey had 66 items and the support group member survey had 88 items. Both versions had numbered sections that included up to 13 different items (i.e. question 2 had items labeled a through m). When we examine the results report provided by Zoomerang®, we see that in addition to the number of individuals that completed the survey, many visited the site and/or took a portion of the survey and did not complete the survey. This suggests that there was some attrition due to the length of the survey. Unfortunately, we were unable to compare the responders to the non-responders as the items referring to the

demographic information were at the end of the survey, and those that did not complete the entire survey did not provide any demographic information.

There were also some theoretical limitations to the study. Social Identity Theory is a group-based framework. Our society is one that is largely individualistic, and thus the application of a collectivistic theory might not be appropriate. Social identities are often derived from cultural meanings and can also be related to a broader cultural context. Cultural values consist of assumptions, beliefs and values. Cultural values influence cooperative behavior either directly or by means of goal relationships. Goal relationships among individuals entails distinguishing between the cooperative behavior and the actions needed to enact the behavior, such as superordinate goals, group identity, trust, accountability, communication, and reward structure with incentives.<sup>5</sup>

Cross-cultural differences in the meaning and treatment of illness can also contribute to variations in illness experience. Belief systems, moral implications, theories of cause, conceptions of body and medical knowledge all contribute to culturally varied illness experiences.<sup>6</sup> Other cultural contexts could include the cultural frames of the health care provider and the patient and a societal focus on medical knowledge and empowerment of the patient. These contexts might influence the attitudes and behaviors of patients and might be difficult to account for in the study.



Longitudinal studies of support are needed. This study was an exploration into the relationships between identity, online support group use and goal attainment processes. The significance of these relationships suggest that there is a causal impact of identity on the goal process, however this needs to be further tested in a larger randomized sample. This study does not determine if online support leads to the maintenance of goal achievement over time or address how the technology can be used to support this process. It is also unclear if this type of support can improve long-term health outcomes or if the health outcomes reported were a result of support or some other factor. A cost effectiveness analysis that measures the benefits costs of online support would add to the findings of this study.

### **Future Studies**

Throughout this chapter I have suggested how the findings of the specific aims can be used to direct future research. There are many different directions that the findings can go in; however, there can also be refinement as well. Refinement of the survey instrument to better address the concepts of illness and social identity in particular or the testing of a larger model that includes constructs for all of the variables that were measured perhaps. Different perspectives can also be used to examine the effects of identity and support groups on self-management: the health care provider perspective, for example. There is a sense of ambivalence from health care providers regarding the benefits of online support groups, or any online health information, in part because there is a dearth of information online that can be inaccurate or not

objective. Additionally, physicians may choose to create their own support site and thus can monitor the types of information that is being exchanged between members and the overall message of the group. These physicians might promote the use of their group as opposed to a group created by non-health care providers. There might be a difference in the types of support provided and the types of interaction that occur between these two types of groups and this may be important to capture.

From a patient perspective it would be interesting to study the characteristics of patients that lead them to support groups, to identify with others, and to set goals. Future studies can try and examine the personality attributes of individuals; such as if the individual is more goal-oriented, more individualistic, has a more holistic approach to care, etc. This study did not really assess these characteristics, however in theory it would appear that certain individuals are more predisposed to joining groups or setting goals.

Other approaches to studying support group participation could center on the life cycle of diabetes and how at certain times in this cycle support group participation patterns may change. There was not enough sensitivity in the range of responses for time since diagnosis to really capture differences in use between the two groups. It is also not clear when a newly diagnosed (characterized in this study as being diagnosed in the past two years) patient came to accept the illness, or when their interactions on the support group changed from maybe information seeking to providing support. These patterns are important to study. Also important to examine are the reasons why people

use online support. This study assessed the main reason the individual joined a support group, however did not really probe into what keeps them coming back, although we can assume that the benefits and outcomes from support group interaction that were reported are likely the reason for repeat visits.

Finally, there are likely differences in identity and interaction between individuals that receive support face-to-face and those that receive it within a virtual community. This study did not capture the differences in these two groups and future studies should assess this.

## **Conclusions**

Structural equation modeling found social identity influenced lifestyle goal setting. Lifestyle goal self-efficacy mediated the relationship between goal setting and achievement in support group members (n=133) and non-support group members (n=253). Illness identity directly influenced lifestyle goal self-efficacy for both groups. For non-support group members, illness identity also influenced medication goal behaviors. Moderated mediation regression demonstrated significant interaction between support group identity and medication goal self-efficacy on goal achievement ( $t = -1.91$   $p = 0.05$ ) in persons in an online support group. Bootstrap estimates for confidence intervals around the mean (2.46) were -0.135 to -0.649 and Sobel test statistic = 2.4799 SE = 0.2909  $p = 0.01$  reveal significant indirect effects. Other regression analyses found that for behaviors related to self-monitoring blood glucose and avoiding certain foods, there was a direct relationship between goal setting and achievement ( $t = 2.68$   $p = 0.008$ ). For

behaviors including eating healthy, exercising and conducting foot exams, goal setting and goal achievement were related ( $t=3.35$   $p=0.001$ ). Setting medication goals significantly predicts medication goal achievement ( $t=5.10$   $p<0.001$ ). Control of diabetes was significantly associated with social identity, the belief that diabetes is controlled by medication, self-monitoring blood glucose levels, and goal self-efficacy and lifestyle goal. Support group membership did improve goal behaviors, particularly medication goals. Social identity also influenced goal setting for lifestyle goals. Illness identity impacted lifestyle goal self-efficacy and medication taking goal behaviors. These findings have implications for the assessment of identity in the provision of healthcare services and the use of support groups in the goal setting process for the self-management of type 2 diabetes.

From a patient care perspective, these findings suggest that online support groups have a positive impact on goal setting and achievement for those members that identify with the group and the objectives of the group. Health care providers that use goal setting to achieve clinical control of type 2 diabetes might find such groups useful tools to assist in setting and achieving goals. Support provided by such groups can also be helpful in educating the patient on methods of treating diabetes and improve the communication between the provider and the patient. Ongoing support is an essential component of mastering goals and healthcare providers should advocate this type of support in conjunction with regular check-ups and in addition to support from family, friends and care providers.

## Notes to Chapter 6

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## **APPENDICES**

# **APPENDIX A**

## **Subject Recruitment Script and Consent Form**

# UNIVERSITY OF MICHIGAN

## CONSENT TO BE PART OF A RESEARCH STUDY

### Name of Study and Researchers

**Title of Project:** The influence of support groups and identity on goal setting and achievement in persons with type 2 diabetes.

**Principal Investigators:** Angela Hagan, MS

**Co-Investigators:** Trisha Wells PharmD, Caroline Gaither PhD, RPh

We are conducting research about the influence of support groups and identity on goal setting and achievement in persons with type 2 diabetes. We would like to gather information about your diabetes, how it affects your life, how you self-manage your condition and whether or not you use a support group in doing so. To gather information, we are asking adults with type 2 diabetes to answer a survey. Right now, the study is at the preliminary stage and your responses to the survey will be useful in creating a survey that will be distributed to a larger patient population. The survey is voluntary. You do not have to complete it or answer questions you don't want to answer. Your responses will help us understand and treat patients with diabetes better.

It will take about 15-20 minutes to complete the questions. There is no charge to you or your health insurance for completing the questionnaire. You will be responsible to record your responses to the survey questions. Some questions may cause you to feel uncomfortable. Like the information in your medical record, your responses to these questions will remain confidential; names and identifying information are not present on the questionnaire. While you will be asked to sign this form, this form will not be linked to your survey responses and you will not be identified in any reports on this study. The records of your responses will be kept confidential to the extent provided by federal, state and local law.

I hope that you can complete this survey. Future patients with diabetes may benefit by the information we learn. The results of this study may result in your health care provider recommending that you seek support from other patients with diabetes if you should need it. As a token of our appreciation for your



participation in this study, you will receive a gift certificate valued up to \$10 for a local grocery or pharmacy to be used as you desire.

If you have any questions regarding the questionnaire or you feel confused by the questions, please either write down your comments on the questionnaire, or talk to me directly about your concerns. If you have questions or concerns about this study or feel that the study has caused you any harm, please contact Angela Hagan, at the Department of Clinical, Social and Administrative Sciences, 734-615-8676 or Dr. Trisha Wells, University of Michigan Health System, Ann Arbor, Michigan 48109, telephone 810-494-2666 If you have any questions or concerns about your rights as a research subject, or any grievance, you may also contact the Institutional Review Board for Human Subject Research (IRBMED), University of Michigan, 517 W. William, Argus I, Ann Arbor, MI 48103-4943; telephone 734 763-4768.

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### SIGNATURES

**Research Subject:**

I understand the information printed on this form. I have discussed this study, its risks and potential benefits, and my other choices with \_\_\_\_\_. My questions so far have been answered. I understand that if I have more questions or concerns about the study or my participation as a research subject, I may contact one of the people listed above. I understand that I will receive a copy of this form at the time I sign it and later upon request. I understand that if my ability to consent for myself changes, either I or my legal representative may be asked to re-consent prior to my continued participation in this study.

Signature of Subject: \_\_\_\_\_ Date: \_\_\_\_\_

Name (Print legal name): \_\_\_\_\_

Study ID: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

self: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

**APPENDIX B**  
**Survey Instrument**

## Support group users survey

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### Patients with type 2 diabetes: identity, support and goals.

Are you a person with type 2 diabetes?

- Yes
- No

The following items ask how you feel about your diabetes on a number of issues. For each item, please tell us how strongly the item describes how you feel about having diabetes. On a scale of 1: does not describe me at all 3: describes me moderately well 5: describes me very well

I believe there is nothing wrong with me

I am certain that my diabetes will be cured

I feel hopeful despite my diabetes

I believe that my diabetes will go away by itself

I feel that there is nothing I can do to help myself

My diabetes must be a punishment for something I did in the past

I am embarrassed or ashamed about having diabetes

When I look at other people in good health, I get envious

I blame myself for having diabetes

I am worried about my diabetes

I am angry about my diabetes

I feel that nothing will ever be the same again

My diabetes makes me feel lonely at times, even when I am with others

For each of the following questions, please tell us how strongly the item describes how you feel about the impact of diabetes on your life. On a scale of 1: doesn't describe me at all to 5: describes me very well.

I am rearranging some of my life priorities having been diagnosed with diabetes.

I am seeking a new meaning for my life having been diagnosed with diabetes.

I accept help when I need it now that I am a person with diabetes.

I am interested in forming new friendships as a person with diabetes.

I am interested in making plans for my future as a person with diabetes.

I am satisfied with my present abilities despite having diabetes.

Despite having diabetes, I can do most things persons without diabetes can do.

I realize that diabetes is a part of me, but I do not let it interfere with my life.

When I look in the mirror, I see myself and not a person with diabetes.

For each of the following items that mention things that are associated with diabetes, please indicate to what degree you agree or disagree. On a scale of 1: not at all 2: a very little bit 3: somewhat 4: moderately 5: quite a bit 6: very much 7: totally

To what extent do you believe that diabetes can be controlled by monitoring blood glucose levels?

To what extent do you believe that diabetes can be controlled by eating healthy foods?

To what extent do you believe that diabetes can be controlled by avoiding certain foods?

To what extent do you believe that diabetes can be controlled by physical exercise?

To what extent do you believe that diabetes can be controlled by medication?

How much does your family and friends accept you as a person with type 2 diabetes?

How comfortable are your family and friends with your diabetes?

How much does your family and friends encourage you to manage your diabetes?

For each of the following individuals, please rate the extent to which each individual assists you in caring for your diabetes. On a scale of 1: does not apply 2: not at all 4: moderately 6: considerably

Spouse or significant other

Children

Other family

Friends

Paid helper

Doctor Nurse

Pharmacist

Other person

Other person (Please specify)

For the following individuals, please rate the extent to which your type 2 diabetes affects your relationships with each individual. On a scale of 1: does not apply 2: not at all 4: moderately 6: considerably

Spouse or significant other

Children

Other family

Care providers (doctor, nurse, pharmacist, etc.)

Employer

Co-workers

Friends

Other

Other person (Please specify)

For the following items, please indicate to what extent your diabetes and its treatment keeps you from doing the activities listed below? On a scale of 1: not at all 3: moderately 5: considerably

Meeting work responsibilities

Meeting household responsibilities

Traveling as much as you want

Being as active as you desire

Having good relationships with people that are important to you

Keeping a schedule you desire]

Spending time with your family and friends

Having enough alone time

Do you wear or carry some kind of diabetes identification?

- Yes
- No

What type of identification do you use? Check all that apply.

- Wallet card
- Bracelet
- Necklace
- Do not use any identification
- Other, please specify

Many people in the United States have type 2 diabetes. Considering all these people and yourself as a group, please tell us to what extent each of the following applies to you personally. On a scale from 1: not at all 3: moderately 5: considerably

To what extent do you think of yourself as a member of the group of all people with type 2 diabetes?

How attached would you say you are to the group of all people with type 2 diabetes?

How strong would you say your feelings of belongingness are towards the group of all people with type 2 diabetes?

For the following questions, please rate the degree to which you agree with the statement about yourself as a person in general. On a scale of 1: strongly disagree 3: neither agree nor disagree 5: strongly agree

On the whole, I am satisfied with myself.

I have a positive attitude toward myself.

I will be able to achieve most of the goals that I have set for myself.

Please indicate the amount of diabetes-specific care the following health care providers administers to you. On a scale of 1: does not provide any care 2: provided care once 3: provides care every once and awhile 4: provides care regularly 5: provides all care

General family physician  
Nurse  
Physician Assistant  
Diabetes Specialist (Endocrinologist)  
Pharmacist  
Other provider

Other provider (please specify)

During the past 3 months, please select the number of visits you made to each health care provider. On a scale of 1: no visits 2: one visit 3: two visits 4: three or more visits

General family physician  
Nurse  
Physician Assistant  
Diabetes Specialist (Endocrinologist)  
Pharmacist  
Other provider

Other (please specify what type of provider)

At any of these visits, did that health care provider discuss setting goals to manage your diabetes? Indicate yes or no.

General family physician  
Nurse  
Physician Assistant  
Diabetes Specialist (Endocrinologist)  
Pharmacist  
Other provider

Other (please specify what type of provider)

For the following items, please rate the extent to which each item is a personal goal you have. On a scale of 1: not a goal at all for me 3: a moderate goal for me 5: a strong goal for me

To monitor blood glucose levels regularly  
To eat healthy foods everyday  
To avoid eating certain foods everyday  
To engage in physical activity regularly  
To conduct foot exams regularly  
To take my diabetes medications as prescribed



Other goal and rating (1-5)

For each of the following goals, please rate your degree of confidence in achieving the goal. On a scale of 1: not at all confident 3: moderately confident 5: very confident

- To monitor blood glucose levels regularly
- To eat healthy foods everyday
- To avoid eating certain foods everyday
- To engage in physical activity regularly
- To conduct foot exams regularly
- To take my diabetes medications as prescribed

Other goal and rating (1-5)

Mark the days during the last week that you achieved the following goals.

Monitored blood glucose levels.

- Not a goal of mine
- Did not achieve this goal any day in the past week
- Achieved this goal 1-2 days in the past week
- Achieved this goal 3-4 days in the past week
- Achieved this goal 5-6 days in the past week
- Achieved this goal every day in the past week

Ate healthy foods.

- Not a goal of mine
- Did not achieve this goal any day in the past week
- Achieved this goal 1-2 days in the past week
- Achieved this goal 3-4 days in the past week
- Achieved this goal 5-6 days in the past week
- Achieved this goal every day in the past week

Avoided eating certain foods.

- Not a goal of mine
- Did not achieve this goal any day in the past week
- Achieved this goal 1-2 days in the past week
- Achieved this goal 3-4 days in the past week
- Achieved this goal 5-6 days in the past week
- Achieved this goal every day in the past week

Engaged in physical activity.

- Not a goal of mine
- Did not achieve this goal any day in the past week
- Achieved this goal 1-2 days in the past week
- Achieved this goal 3-4 days in the past week
- Achieved this goal 5-6 days in the past week
- Achieved this goal every day in the past week

Conducted a foot exam.

- Not a goal of mine
- Did not achieve this goal any day in the past week
- Achieved this goal 1-2 days in the past week
- Achieved this goal 3-4 days in the past week
- Achieved this goal 5-6 days in the past week
- Achieved this goal every day in the past week

Took my diabetes medications as prescribed.

- Not a goal of mine
- Did not achieve this goal any day in the past week
- Achieved this goal 1-2 days in the past week
- Achieved this goal 3-4 days in the past week
- Achieved this goal 5-6 days in the past week
- Achieved this goal every day in the past week

Have you ever received diabetes education? (for example: attended a series of classes or series of meetings with a diabetes educator)

- Yes
- No
- Not sure

Have you ever participated in any type of support group for type 2 diabetes? (Indicate all that apply)

- No, I have not participated in any type of support group
- Yes, I have participated in a support group online
- Yes, I have participated in a support group face-to-face

How many online support groups are you a registered member of?

- One
- Two
- Three or more

What is the name of the support group you participate the most in?

- Diabetes Daily
- Defeat Diabetes
- Daily Strength
- Alt-Support Diabetes
- dLife
- TuDiabetes
- Other, please specify

How often do you visit the online support group you listed above?

- Once, but never visited again
- Visit about 1-4 times a year
- Visit about 5-8 times a year
- Visit about 9-12 times a year
- Visit about 2-3 times a month
- Visit about once a week
- Visit about 2-4 times a week
- Visit about 5-7 times a week
- Once a day
- More than once a day

What is the main reason you joined an online support group for type 2 diabetes?

- I felt that belonging to a group would benefit me
- I did not feel as though I had enough support from family and friends
- I did not feel as though I had enough support from my healthcare providers
- One of my health care providers recommended I join an online group
- Someone else recommended I join an online group
- My interactions in a face-to-face support group led me to join an online group
- I wanted to meet other people with type 2 diabetes
- I needed help managing my type 2 diabetes
- Other, please specify

For the following activities one can participate in as a member of an online support group, please indicate how often you engage in the following activities. On a scale of 1: have never done this 2: almost never 4: moderately often 6: very often

Participate in support forums and chat rooms

Read blogs or topics posted by others

Post my own blog or topic

Respond to blogs or topics posted by others

Search for diabetes-related information on treatment (medications)

Search for diabetes-related information on nutrition (diet tips, recipes)

Set a diabetes-related goal and monitor my progress toward goal

Please rate how often the following occurs in your online support group. On a scale of 1: this has never happened 2: happens sometimes 3: happens regularly 4: happens often 5: happens a lot

Another member shows empathy toward you

Another member consoles you

Another member provides encouragement to you

Another member pays you a compliment

Another member reassures you

Another member confides in you

Please rate how often the following occurs in your online support group. On a scale of 1: this has never happened 2: happens sometimes 3: happens regularly 4: happens often 5: happens a lot

You see yourself in the experiences other members post

You feel as though you are not the only one

You are a role model to other members

You share your illness experience with other members

You are looked upon to offer guidance and support

Please answer the following questions about the online diabetes support group you belong to.

To what extent do you identify with your online diabetes support group? On a scale of 1: don't identify at all 3: identify moderately with 5: identify very much with

To what extent does your own self-image overlap with the image of those in your online diabetes support group? On a scale of 1: no overlap at all 3: moderate overlap 5: nearly total overlap

How involved are you with your online diabetes support group? On a scale of 1: not involved at all 3: moderately involved 5: very much involved

How attached are you to your online diabetes support group? On a scale of 1: not attached at all 3: moderately attached 5: very much attached

How strong would you say your feelings of belongingness are with your online diabetes support group? On a scale of 1: not strong at all 3: moderately strong 5: very strong

How committed are you to your online diabetes support group? On a scale of 1: not committed at all 3: moderately committed 5: very much committed

To what degree does your membership in your online diabetes support group give you feelings of respect from others? On a scale of 1: very little respect 3: moderate respect 5: a lot of respect

To what degree does your membership in your online diabetes support group give you feelings of admiration by others? On a scale of 1: very little admiration 3: moderate admiration 5: a lot of admiration

To what degree does your membership in your online diabetes support group give you feelings of self-worth? On a scale of 1: very little self-worth 3: moderate self-worth 5: a lot of self-worth

For the following statements, please indicate the extent to which each statement describes you and your membership in an online diabetes support group. On a scale of 1: doesn't describe me at all 3: describes me somewhat 5: describes me very well

I am a valuable member of my diabetes support group

I am an important member of my diabetes support group

I think my diabetes support group has a lot to be proud of

- I tell others that I belong to a diabetes support group
- I identify with other members of my diabetes support group
- I am like other members of my diabetes support group
- My diabetes support group is an important reflection of who I am

For the following statements about membership in an online diabetes support group, please rate the extent to which each statement is true. On a scale of 1: not at all true 3: moderately true 5: very true

- Provided you with useful diabetes-related advice
- Provided you with useful diabetes-related information
- Helped you set goals to self-manage your diabetes
- Improved your confidence to achieve diabetes-related goals
- Increased your acceptance of diabetes
- Provided feedback and encouragement on goal-related behavior
- Made you feel better prepared for your next appointment with a healthcare provider
- Improved your feelings of control over your diabetes
- Increased feelings of self-worth

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What is your gender?

- Male
- Female

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What is your ethnic origin/race?

- Non-Hispanic White
- Non-Hispanic Black
- Hispanic
- Asian or Pacific Islander
- Native American
- Other, please specify

In what region of the US do you reside?

- Northeast (ME,NH,VT,MA,RI,CT,NY,NJ,PA)
- Midwest (OH,MI,IN,WI,IL,MN,IA,MO,ND,SD,NE,KS)
- West (MT,WY,CO,NM,ID,UT,AZ,NV,WA,OR,CA,AK,HI)
- South (TX,OK,AR,LA,MS,KY,TN,AL,DE,MD,DC,VA,WV,NC,SC,GA,FL)

In which of the following age groups do you belong?

- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65+

When were you diagnosed with diabetes?

- 0-2 years ago
- 3-5 years ago
- 6-8 years ago
- 9-10 years ago
- More than 10 years ago

Your last hemoglobin A1c test (HbA1c) was:

- Within the past 3 months
- Within the past 6 months
- Within the past year
- 1-2 years ago
- Never had a Hemoglobin A1c test

The last time your hemoglobin A1c was tested, the value was

- Below 6.0
- Between 6.0 and 7.0
- Between 7.0 and 8.0
- Above 8.0
- Don't remember
- Have never had an HbA1c test

Are you now taking oral diabetes medications for your diabetes?

- Yes
- No

Are you now taking insulin for your diabetes?

- Yes
- No

What is your marital status?

- Never married
- Currently married
- Separated/divorced
- Widowed

Which of the categories best describes your total annual combined household income from all sources?

- Less than \$10,000
- \$10,000 to \$19,999
- \$20,000 to \$29,999
- \$30,000 to \$39,999
- \$40,000 to \$49,999
- \$50,000 to \$59,999
- \$60,000 to \$69,999
- \$70,000 to \$79,999
- \$80,000 to \$89,999
- \$90,000 to \$99,999
- over \$100,000

How much schooling have you had?

- Some high school
- High school graduate or GED
- Some college or technical school
- College graduate (bachelor's degree)
- Graduate degree



## Non-support group users survey

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### Patients with type 2 diabetes: identity, support and goals.

What is your gender?

- Male
- Female

What is your ethnic origin/race?

- Non-Hispanic White
- Non-Hispanic Black
- Hispanic
- Asian or Pacific Islander
- Native American
- Other, please specify

The following items ask how you feel about your diabetes on a number of issues. For each item, please tell us how strongly the item describes how you feel about having diabetes. On a scale of 1: does not describe me at all 3: describes me moderately well 5: describes me very well

I believe there is nothing wrong with me

I am certain that my diabetes will be cured

I feel hopeful despite my diabetes

I believe that my diabetes will go away by itself

I feel that there is nothing I can do to help myself

My diabetes must be a punishment for something I did in the past

I am embarrassed or ashamed about having diabetes

When I look at other people in good health, I get envious

I blame myself for having diabetes

I am worried about my diabetes

I am angry about my diabetes

I feel that nothing will ever be the same again

My diabetes makes me feel lonely at times, even when I am with others

For each of the following questions, please tell us how strongly the item describes how you feel about the impact of diabetes on your life. On a scale of 1: doesn't describe me at all to 5: describes me very well.

I am rearranging some of my life priorities having been diagnosed with diabetes.

I am seeking a new meaning for my life having been diagnosed with diabetes.

I accept help when I need it now that I am a person with diabetes.

I am interested in forming new friendships as a person with diabetes.

I am interested in making plans for my future as a person with diabetes.

I am satisfied with my present abilities despite having diabetes.

Despite having diabetes, I can do most things persons without diabetes can do.

I realize that diabetes is a part of me, but I do not let it interfere with my life.

When I look in the mirror, I see myself and not a person with diabetes.

For each of the following items that mention things that are associated with diabetes, please indicate to what degree you agree or disagree. On a scale of 1: not at all 2: a very little bit 3: somewhat 4: moderately 5: quite a bit 6: very much 7: totally

To what extent do you believe that diabetes can be controlled by monitoring blood glucose levels?

To what extent do you believe that diabetes can be controlled by eating healthy foods?

To what extent do you believe that diabetes can be controlled by avoiding certain foods?

To what extent do you believe that diabetes can be controlled by physical exercise?

To what extent do you believe that diabetes can be controlled by medication?

How much does your family and friends accept you as a person with type 2 diabetes?

How comfortable are your family and friends with your diabetes?

How much does your family and friends encourage you to manage your diabetes?

For each of the following individuals, please rate the extent to which each individual assists you in caring for your diabetes. On a scale of 1: does not apply 2: not at all 4: moderately 6: considerably

Spouse or significant other

Children

Other family

Friends

Paid helper

Doctor Nurse

Pharmacist

Other person

Other person (Please specify)

For the following individuals, please rate the extent to which your type 2 diabetes affects your relationships with each individual. On a scale of 1: does not apply 2: not at all 4: moderately 6: considerably

Spouse or significant other

Children

Other family

Care providers (doctor, nurse, pharmacist, etc.)

Employer

Co-workers

Friends

Other

Other person (Please specify)

For the following items, please indicate to what extent your diabetes and its treatment keeps you from doing the activities listed below? On a scale of 1: not at all 3: moderately 5: considerably

Meeting work responsibilities

Meeting household responsibilities

Traveling as much as you want

Being as active as you desire

Having good relationships with people that are important to you

Keeping a schedule you desire]

Spending time with your family and friends

Having enough alone time

Do you wear or carry some kind of diabetes identification?

- Yes
- No

What type of identification do you use? Check all that apply.

- Wallet card
- Bracelet
- Necklace
- Do not use any identification
- Other, please specify

Many people in the United States have type 2 diabetes. Considering all these people and yourself as a group, please tell us to what extent each of the following applies to you personally. On a scale from 1: not at all 3: moderately 5: considerably

To what extent do you think of yourself as a member of the group of all people with type 2 diabetes?

How attached would you say you are to the group of all people with type 2 diabetes?

How strong would you say your feelings of belongingness are towards the group of all people with type 2 diabetes?

For the following questions, please rate the degree to which you agree with the statement about yourself as a person in general. On a scale of 1: strongly disagree 3: neither agree nor disagree 5: strongly agree

On the whole, I am satisfied with myself.

I have a positive attitude toward myself.

I will be able to achieve most of the goals that I have set for myself.

Please indicate the amount of diabetes-specific care the following health care providers administers to you. On a scale of 1: does not provide any care 2: provided care once 3: provides care every once and awhile 4: provides care regularly 5: provides all care

General family physician  
Nurse  
Physician Assistant  
Diabetes Specialist (Endocrinologist)  
Pharmacist  
Other provider

Other provider (please specify)

During the past 3 months, please select the number of visits you made to each health care provider. On a scale of 1: no visits 2: one visit 3: two visits 4: three or more visits

General family physician  
Nurse  
Physician Assistant  
Diabetes Specialist (Endocrinologist)  
Pharmacist  
Other provider

Other (please specify what type of provider)

At any of these visits, did that health care provider discuss setting goals to manage your diabetes? Indicate yes or no.

General family physician  
Nurse  
Physician Assistant  
Diabetes Specialist (Endocrinologist)  
Pharmacist  
Other provider

Other (please specify what type of provider)

For the following items, please rate the extent to which each item is a personal goal you have. On a scale of 1: not a goal at all for me 3: a moderate goal for me 5: a strong goal for me

To monitor blood glucose levels regularly  
To eat healthy foods everyday  
To avoid eating certain foods everyday  
To engage in physical activity regularly  
To conduct foot exams regularly  
To take my diabetes medications as prescribed

Other goal and rating (1-5)

For each of the following goals, please rate your degree of confidence in achieving the goal. On a scale of 1: not at all confident 3: moderately confident 5: very confident

- To monitor blood glucose levels regularly
- To eat healthy foods everyday
- To avoid eating certain foods everyday
- To engage in physical activity regularly
- To conduct foot exams regularly
- To take my diabetes medications as prescribed

Other goal and rating (1-5)

Mark the days during the last week that you achieved the following goals.

Monitored blood glucose levels.

- Not a goal of mine
- Did not achieve this goal any day in the past week
- Achieved this goal 1-2 days in the past week
- Achieved this goal 3-4 days in the past week
- Achieved this goal 5-6 days in the past week
- Achieved this goal every day in the past week

Ate healthy foods.

- Not a goal of mine
- Did not achieve this goal any day in the past week
- Achieved this goal 1-2 days in the past week
- Achieved this goal 3-4 days in the past week
- Achieved this goal 5-6 days in the past week
- Achieved this goal every day in the past week

Avoided eating certain foods.

- Not a goal of mine
- Did not achieve this goal any day in the past week
- Achieved this goal 1-2 days in the past week
- Achieved this goal 3-4 days in the past week
- Achieved this goal 5-6 days in the past week
- Achieved this goal every day in the past week

Engaged in physical activity.

- Not a goal of mine
- Did not achieve this goal any day in the past week
- Achieved this goal 1-2 days in the past week
- Achieved this goal 3-4 days in the past week
- Achieved this goal 5-6 days in the past week
- Achieved this goal every day in the past week

Conducted a foot exam.

- Not a goal of mine
- Did not achieve this goal any day in the past week
- Achieved this goal 1-2 days in the past week
- Achieved this goal 3-4 days in the past week
- Achieved this goal 5-6 days in the past week
- Achieved this goal every day in the past week

Took my diabetes medications as prescribed.

- Not a goal of mine
- Did not achieve this goal any day in the past week
- Achieved this goal 1-2 days in the past week
- Achieved this goal 3-4 days in the past week
- Achieved this goal 5-6 days in the past week
- Achieved this goal every day in the past week

Have you ever received diabetes education? (for example: attended a series of classes or series of meetings with a diabetes educator)

- Yes
- No
- Not sure

Have you ever participated in any type of support group for type 2 diabetes? (Indicate all that apply)

- No, I have not participated in any type of support group
- Yes, I have participated in a support group online
- Yes, I have participated in a support group face-to-face

Would you consider joining an online support group for type 2 diabetes?

- Yes
- No



What is the main reason you would not join an online support group for type 2 diabetes?

- Not interested in such groups
- Don't have time to participate
- Do not feel that such groups would benefit me
- Have enough support from family and friends
- Have enough support from my healthcare providers
- Have other health conditions for which I belong to a support group
- I prefer interacting with others face-to-face
- Other, please specify

For the following activities one can participate in as a member of an online support group, please indicate how likely you would be to engage in the following activities. On a scale of 1: not at all likely 3: moderately likely 5: very likely \*\*\*\*\*Question not mandatory

Participate in support forums and chat rooms

Read blogs or topics posted by others

Post my own blog or topic

Respond to blogs or topics posted by others

Search for diabetes-related information on treatment (medications)

Search for diabetes-related information on nutrition (diet tips, recipes)

Set a diabetes-related goal and monitor my progress toward goal

For the following statements about membership in an online diabetes support group, please rate the extent to which you think each statement would be true. On a scale of 1: not at all true 3: moderately true 5: very true \*\*\*\*\*Question not mandatory

Allow you to share your diabetes-related problems with other

Allow you to receive diabetes-related support from others

Provide you with useful diabetes-related advice

Provide you with useful diabetes-related information

Help you set goals to self-manage your diabetes

Improve your confidence to achieve diabetes-related goals

Provide feedback and encouragement on goal-related behavior

In what region of the US do you reside?

- Northeast (ME,NH,VT,MA,RI,CT,NY,NJ,PA)
- Midwest (OH,MI,IN,WI,IL,MN,IA,MO,ND,SD,NE,KS)
- West (MT,WY,CO,NM,ID,UT,AZ,NV,WA,OR,CA,AK,HI)
- South (TX,OK,AR,LA,MS,KY,TN,AL,DE,MD,DC,VA,WV,NC,SC,GA,FL)

In which of the following age groups do you belong?

- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65+

When were you diagnosed with diabetes?

- 0-2 years ago
- 3-5 years ago
- 6-8 years ago
- 9-10 years ago
- More than 10 years ago

Your last hemoglobin A1c test (HbA1c) was:

- Within the past 3 months
- Within the past 6 months
- Within the past year
- 1-2 years ago
- Never had a Hemoglobin A1c test

The last time your hemoglobin A1c was tested, the value was

- Below 6.0
- Between 6.0 and 7.0
- Between 7.0 and 8.0
- Above 8.0
- Don't remember
- 
- 
- Have never had an HbA1c test

Are you now taking oral diabetes medications for your diabetes?

- Yes
- No

Are you now taking insulin for your diabetes?

- Yes
- No

What is your marital status?

- Never married
- Currently married
- Separated/divorced
- Widowed

Which of the categories best describes your total annual combined household income from all sources?

- Less than \$10,000
- \$10,000 to \$19,999
- \$20,000 to \$29,999
- \$30,000 to \$39,999
- \$40,000 to \$49,999
- \$50,000 to \$59,999
- \$60,000 to \$69,999
- \$70,000 to \$79,999
- \$80,000 to \$89,999
- \$90,000 to \$99,999
- over \$100,000

How much schooling have you had?

- Some high school
- High school graduate or GED
- Some college or technical school
- College graduate (bachelor's degree)
- Graduate degree

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