


Spring 5-15-2017

# Exploring Autonomy Support in Shared Decision Making and Patient Activation of Diabetes Self-Care Behaviors

Carol Mahler Hamersky  
Seton Hall University, [carol.hamersky@student.shu.edu](mailto:carol.hamersky@student.shu.edu)

Follow this and additional works at: <https://scholarship.shu.edu/dissertations>

 Part of the [Endocrinology, Diabetes, and Metabolism Commons](#), [Family Medicine Commons](#), [Internal Medicine Commons](#), [Nutritional and Metabolic Diseases Commons](#), and the [Social and Behavioral Sciences Commons](#)

---

## Recommended Citation

Hamersky, Carol Mahler, "Exploring Autonomy Support in Shared Decision Making and Patient Activation of Diabetes Self-Care Behaviors" (2017). *Seton Hall University Dissertations and Theses (ETDs)*. 2243.  
<https://scholarship.shu.edu/dissertations/2243>

**EXPLORING AUTONOMY SUPPORT IN SHARED DECISION MAKING AND  
PATIENT ACTIVATION OF DIABETES SELF-CARE BEHAVIORS**

By

Carol Mahler Hamersky

Dissertation Committee:

Dr. Genevieve Pinto-Zipp, Chair

Dr. Deborah DeLuca

Dr. Ning Jackie Zhang

Graduate Program in Health Sciences

Seton Hall University

2017

Submitted in fulfillment of the requirements for the degree of

Doctor of Philosophy in Health Sciences

Seton Hall University

2017

© 2017 Carol M. Hamersky

**All Rights Reserved**

**Seton Hall University**  
**School of Health and Medical Sciences**  
**Department of Interprofessional Health Sciences and Health Administration**

**Approval of Successful Defense**

Doctoral Candidate, Carol Mahler Hamersky, has successfully defended  
and made the required modifications to the text of the doctoral  
dissertation for Ph.D. during the **Spring Semester 2017**.

**Dissertation Committee:**

Dr. Genevieve Pinto Zipp, Chair

Dr. Deborah DeLuca

Dr. Ning Jackie Zhang

**Approved by the Dissertation Committee**

Dr. Genevieve Pinto-Zipp

 \_\_\_\_\_ Date 2/8/17

Dr. Dr. Deborah DeLuca

 \_\_\_\_\_ Date 2/8/17

Dr. Ning Jackie Zhang

 \_\_\_\_\_ Date 2/8/17

## ACKNOWLEDGEMENTS

Many individuals have been instrumental in supporting my PhD journey and completion of my dissertation work. First, I would like to express my sincere appreciation to my dissertation committee members, Dr. Genevieve Pinto-Zipp, Dr. Deborah DeLuca and Dr. Ning Jackie Zhang for their guidance and support during this process.

Dr. Zipp for your expert guidance and endless support from the beginning of the doctoral program through the defense. You always knew exactly what to say to help me relax, then move forward to another layer of critical thinking. I know now why your signature includes your favorite quote “seeking the best in others, we find the best in ourselves”. Thank you for mentoring me in my pursuit of this lifelong goal.

Dr. DeLuca for sharing your love of theory and challenging me to remain unbiased as I searched the literature and prepared my scholarly questions and work. Your early class advisement in scientific writing and delivering a short elevator speech truly helped me narrow down my research interests.

Dr. Zhang, thank you for your depth of knowledge in research methodology, patience in teaching and bringing strengths and limitations of all research to LIFE. Never did I think I would be explaining threats to internal, external, and conclusion validity to other future scholars.

Finally, and most importantly, I would like to thank my family. To my husband, Rich who has supported me throughout my academic and professional career. You have provided me with strength and encouragement especially when it was most needed. To my daughter, Kerri, who provided me with valuable insight and support, especially in my final dissertation year. I look forward to watching you succeed in your physical therapy career. To my son, Chris, who inspires me with his own depth of knowledge and professional aspirations in pursuing law.

Lastly, to my parents Donald and Olga Mahler for their unconditional love, faith and instilling in me a passion for lifelong learning.

## **Exploring Autonomy Support in Shared Decision Making and Patient Activation of Diabetes Self-Care Behaviors**

Carol Mahler Hamersky

Seton Hall University

Dr. Genevieve Pinto-Zipp

### **Abstract**

Chronic disease places a different set of demands on an individual and family. Self-care behaviors and daily decision making is an integral part of diabetes management. According to the CDC (2014), the prevalence of Diabetes is estimated at 29.1 million and an alarming 86 million Americans have Pre-diabetes. Individualizing care was made prominent in a 2012 joint position paper (Inzucchi et.al) by the American Diabetes Association (ADA) and the European Association for the Study of Diabetes (EASD), the leading organizations in Diabetes care. The position paper explained that individualizing all aspects of diabetes care is critical as so much of the responsibility lies with the patient. They are managing their illness every day and only periodically seeing their healthcare providers (Inzucchi, et al., 2012). Despite a plethora of evidence on the importance of diabetes self-care behaviors on clinical outcomes, large observational studies (Peyrot, et al., 2005 & 2013) have highlighted the current disconnect of patients not able to follow self-care behavior recommendations and not asking for help from their health care providers. There is no literature on the impact of an autonomy supported healthcare environment in shared decision making and patient activation levels of diabetes self-care behaviors. To understand if a relationship exists would provide insight for clinicians to assist their patients in improving their ability to maintain these essential self-care behaviors as part of

their treatment.

Methods: This non-experimental, observational study investigated the relationship between the patient's perceived autonomy support in a shared decision making encounter and their patient activation levels of diabetes self-care behaviors. The study design included both quantitative and qualitative methodology for exploratory, descriptive, and correlational research. The research study which addresses the patients perceived level of autonomy support and their patient activation levels was sent to patients from the Geisinger Health System Endocrinology clinic and Community Practice Service Line Clinics (CPSL). All patients screened who met the diagnostic criteria for Diabetes and additional inclusion criteria were eligible to receive the electronic survey. Electronic survey distribution was sent via mass email distribution per protocol specifications of Geisinger Health System. Approximately 503 subjects received the participant solicitation email/letter of consent with instructions and link to the Survey Monkey anonymous questionnaire. A sample of 101 patients participated in this study.

Results: Mean duration of diabetes was 13 years with a range of 1-40 years living with diabetes. Gender was reported as 40% male and 60% female for those completing the survey. Only 22% of responders did not receive and previous diabetes education sessions.

Perceived autonomy support explained about 23% of the shared variance with Patient activation. Analysis on the relationship between gender on Patient activation levels was weak. The association between DOD and patient activation level was weak and negative (those with longer duration of diabetes had slightly lower patient activation scores. There was no relationship between the number of diabetes education session and patient activation levels. In the linear



multiple regression model including four predictor variables on patient activation, the amount of variance explained increased to 27% and slightly higher than that explained by perceived autonomy support on patient activation scores alone. The only two variables of significance in the model were duration of diabetes and perceived autonomy support.

Qualitative findings revealed responses analogous with perceive autonomy support and feeling comfortable in the healthcare encounter. This included 33% of the patient responding in themes related to “feeling valued, understood and respected with caring professionals”. In comparison, another 33% of patients described their visits with time limitations and even negative emotions experienced. The second question which queried the patient on the most important factors to them in their diabetes healthcare visit, three aligned (71%) with the importance of an autonomy supported environment.

Conclusion: This study increases our understanding of perceived autonomy support in shared decision making and patient activation levels for diabetes self-care behaviors. Helping patients to initiate and maintain these self-care behaviors must remain a priority now and in the future. Greater than 25 % of patients suggest that perceived autonomy support in shard decision making does enhance patient activation levels (scores). Multiple themes including feeling valued, supported, and encouraged in the healthcare interaction were dominant areas of importance based on qualitative analysis of survey responders. These themes are analogous with an autonomy supported environment. In healthcare practices, we can increase patients perceived autonomy support and thus increase patient activation score in patients with diabetes

## TABLE OF CONTENTS

ACKNOWLEDGEMENTS .....	4
ABSTRACT.....	6
LIST OF TABLES .....	11
LIST OF FIGURES .....	12
I. INTRODUCTION	
Background of the Problem.....	14
Purpose of the Study .....	16
Significance of the Study .....	16
Conceptual Framework .....	18
Research Questions and Hypotheses.....	22
II. REVIEW OF THE LITERATURE	
Definition of Terms.....	24
Importance of Diabetes self-care behaviors .....	25
Need for improvement in Diabetes self-care .....	27
ADA Position Paper on Diabetes Management 2012.....	28
Patient Centered Care.....	29

Shared Decision Making .....	32
Charles Model of Shared Decision Making .....	33
Shared Decision Making Tools .....	34
Patient Activation.....	36
Health Care Climate Questionnaire .....	37
Patient Activation Measure (PAM 13) .....	39
Discussion .....	43
III. METHODOLOGY	
Design and Approach.....	45
Sample and Setting.....	46
Instrumentation .....	48
Procedure .....	50
Data Analysis .....	52
IV. RESULTS	
Introduction .....	53
Demographic Sample Information .....	54
Quantitative Findings .....	54
Qualitative Findings.....	73

## V. DISCUSSION AND CONCLUSIONS

Discussion .....	76
Limitations .....	82
Future Research .....	83
Conclusion .....	84
REFERENCES .....	85
APPENDIX A SHU IRB Approval.....	105
APPENDIX B Geisinger Health System IRB Approval .....	108
APPENDIX C Letter of Solicitation for Participation .....	112
APPENDIX D Patient Survey .....	114
APPENDIX E G*Power Post hoc Analyses .....	122

## LIST OF TABLES

Table 1.	Frequency & Percentage of Medical Clinics .....	.54
Table 2.	Frequency & Percentages of Respondents per Gender .....	.55
Table 3.	Frequency & Percentages of Diabetes Education Session .....	.57
Table 4.	Central Tendency Dispersion Duration of Diabetes .....	.59
Table 5.	Tests of Normality Duration of Diabetes .....	.59
Table 6.	Central Tendency Dispersion Perceived Autonomy Support .....	.61
Table 7.	Tests of Normality Perceived Autonomy Support .....	.61
Table 8.	Pearson's Correlation Perceived Autonomy Support & Pt Act Score. ....	.63
Table 9.	Spearman's Rho Correlation Gender & Patient Activation Score .....	.64
Table 10.	Pearson's Correlation Duration of Diabetes & Pt Activation Score... ..	.65
Table 11.	Spearman's Rho Correlation Diabetes Ed & Pt Activation Score .....	.66
Table 12.	Tests of Normality Patient Activation Score .....	.68
Table 13.	Multiple Regression Coefficient Table .....	.69
Table 14.	Multiple Regression Model Summary .....	.71
Table 15.	Multiple Regression ANOVA Table .....	.71
Table 16.	Frequency & Percentages of Patient Activation Level .....	.72
Table 17.	Open Ended Question 1 .....	.74
Table 18.	Open Ended Question 2 .....	.75

## LIST OF FIGURES

Figure 1.	Bar Graph of Age of Respondents.....	56
Figure 2.	Bar Graph of Level of Formal Education of Respondents... ..	57
Figure 3.	Bar Graph displaying Diabetes Education Sessions .....	58
Figure 4.	Histogram Frequency of Duration of Diabetes .....	60
Figure 5.	Histogram Frequency of Perceived Autonomy Support .....	62
Figure 6.	Scatterplot of Correlation Perceived Autonomy Support & Patient Activation Score .....	64
Figure 7.	Scatterplot of Duration of Diabetes & Patient Activation Score.....	66
Figure 8.	Box Plot on Predictive Variable Perceived Autonomy Support .....	68
Figure 9.	Box Plot on Predictive Variable Duration of Diabetes .....	68
Figure 10.	Normal Probability Plot of The Regression Standardized Residual .....	71
Figure 11.	Scatterplot of Standard Residuals for Model .....	70
Figure 12.	Histogram of Respondents of Patient Activation Scores .....	72

## **Chapter I INTRODUCTION**

### **Background of the Problem**

Chronic diseases and conditions such as heart disease, stroke, cancer, and diabetes— are among the most common, costly, and preventable of all health problems. As of 2012, 117 million people in the US, about half of all adults, have one or more chronic health conditions. One of four adults has two or more chronic health conditions (Ward, 2014). Chronic illness places a different set of demands on patients and their families than an acute illness or injury. They are different in their time course and severity, but also in their requirements for continuous decision making and adjustments to changing circumstances (Wagner, et al., 2005). In 2002, Bodenheimer, Lorig, Holman and Grumbach (2002), reported that chronic disease spans all generations and the prevalence will continue to increase with the aging baby boomer generation. It has been suggested that the boomers' generation will bring to the health care system a high level of sophistication regarding the movement of self-care, wellness and alter the traditional doctor-patient relationship (Institute for the Future, 2000).

The National Diabetes Statistics Report, (2014) estimates the prevalence of Diabetes at 29.1 million or 9.3% of the U.S. population. Of this total 21.0 million have been diagnosed and another 8.1 million are undiagnosed. Additionally, 86 million Americans aged 20 years or older have pre-diabetes (Centers for Disease Control and Prevention, (CDC), 2014; American Diabetes Association (ADA), 2014) and are likely to

progress to diabetes without significant changes in lifestyle and the same participation in diabetes self care (DPP Research Group, 2015)..

Treatment of diabetes involves complex changes in basic behaviors and adherence to complicated regimens. In 2003, the American Association of Diabetes Educators (AADE) identified seven diabetes self-care behaviors as key behaviors in diabetes self-management (Mulcahy, et al., 2003). These core measures of outcome performance are commonly referred to as the AADE7™ (Haas, et al., 2013). The AADE7™ self-care behaviors include healthy eating, being active, monitoring blood glucose, taking medication, problem solving, healthy coping and reducing risk (Tomky, Cypress, Dang, Maryniuk, & Peyrot, 2008; Mulcahy et al., 2003). The AADE7™ core measures are incorporated into the National Standards for Diabetes Self-Management Education and Support (NSDSMES) and are considered the gold standard for helping patients live with diabetes (Hass et al., 2013) and achieving positive health outcomes.

Patients are managing their illness every day and only periodically see their health care providers. Individualizing all aspects of diabetes care is critical as so much of the responsibility lies with the patient (Inzucchi, et.al. 2012). This information leads this researcher to explore the importance of perceived autonomy support in shared decisions of healthcare interactions and patient activation levels of diabetes self-care behaviors. .



### **Purpose of the Study**

The central purpose of the study is to explore if a relationship exists between autonomy support in shared decision making and patient activation of self-care behaviors in patients with diabetes.

More specifically, the purpose of the study is:

1. To explore if a relationship exists between autonomy support in shared decision making and patient activation of diabetes self-care behaviors.
2. If a relationship does exist between a patients perceived autonomy support in the shared decision process of their health care interaction and their activation levels of self-care further, to further understand more about the relationship through quantitative and qualitative data
3. To ultimately improve patient activation levels or their ability to maintain these self-care behaviors

### **Significance of the Study**

National data from 1980 to 2012 confirmed the doubling of the incidence and prevalence of diabetes from 1990-2008, and a plateauing between 2008 and 2012. While this is the first report demonstrating any slowing in diabetes prevalence, the trend did not pertain to non-Hispanic black and Hispanic populations or those with a high school education or less (Geiss, et al., 2014). Diabetes is clearly a complex problem with the daily demands of self-care behaviors required to help patients improve their health outcomes

A plethora of evidence exists in the literature supporting the importance of these diabetes self-care behaviors including exercise, healthy eating and taking medications on clinical outcomes. For example, structured exercise interventions of at least 8 weeks' duration have been shown to lower A1C by an average of 0.66% in people with type 2 diabetes, even with no significant change in BMI. Higher levels of exercise intensity are associated with greater improvements in A1C and in fitness and other benefits include slowing the decline in mobility among overweight patients with diabetes (Boul'e, Haddad, Kenny, Wells, & Sigal, 2003; Rejeski, et al, 2012).

Comprehensive programs including nutrition therapy or individualized education sessions have reported A1C decreases of 0.3–1% for type 1 diabetes (DAFNE Study Group, 2002) (Kulkarni, Castle, Gregory, & et.al., 1998) and 0.5–2% for type 2 diabetes (UK Prospective Diabetes Study (UKPDS),1998; Ash, et al., 2003; Rickheim, Weaver, Flader, & Kendall, 2002; Miller, Edwards, Kissling, & Sanville, 2002). Simple diabetes meal planning approach such as portion control or healthful food choices may be better suited for individuals with health literacy and numeracy concerns in improving glycemic control (Goldhaber-Fiebert, Trist'an, & Nathan, 2003; Ziemer, Berkowitz, & Panayioto, 2003).

Similarly, evidence exists supporting the importance of taking medications on improving glycemic and other clinical outcomes. However, multiple factors have been observed to impede adherence to medications regimen, with a link between poor medication adherence and poorer outcomes noted (Skaer, Selar, Markowski, & Won, 1993; Krapek, King, Warren, & et al., 2004). Schafer et al reported that patients need to be

empowered and knowledgeable about each medication, including its action, side effects, efficacy, toxicity, prescribed dosage, appropriate timing, and frequency of administration (AADE, 2009). Finally, Cornell et al., found that diabetes educators and other clinical providers need to look at the patient as a whole; respecting the patient's right to make decisions and taking into consideration lifestyle factors that will impact taking medication and other AADE7 behaviors (Cornell, et al., 2011).

Despite the positive evidence that exists between diabetes self-management behaviors on clinical outcomes, a disconnect exists in helping patients maintain these behaviors. Understanding the circumstances that enable patients to adhere to overall diabetes treatment is a key step in development of effective interventions now and in the future (Golin, DiMatteo, & Gelberg, 1996). According to Shortus et.al (2013), involving patients in their care may be a means to an end rather than an end itself, meaning it will help to include them in their care but it may not be a simple solution. Understanding the relationship between autonomy support in shared decision making and levels of patient activation may provide valuable clinical insight for clinicians trying to assist their patients in maintaining diabetes self-care behaviors and ultimately health outcomes.

### **Conceptual Framework**

Two theoretical perspectives guide this exploration, The Self-Determination Theory (SDT) introduced by Deci & Ryan, (1985) and the Social Cognitive Theory by Bandura (1977). Both of these theories independently support a critical direction on the importance

of medical encounters with shared decision making and specifically the patient's role in self-management behaviors as part of the overall management of diabetes. Taken together these theories create a theoretical framework to move forward and explore the question, "Will patients who perceive they have autonomy support via patient centered care practices vs controlled environment (physician centric) in their ongoing healthcare encounters have differences in activation of diabetes self-care behaviors?"

One of the central tenets of the Social Determination Theory is that the quality of the environment influences the motivation, performance and well-being of the individuals within them (Ryan & Deci, 2000). Vital to the SDT is the concepts of autonomous vs controlled motivation and perceived competence versus incompetence. According to Williams et al. (1998), people are autonomously motivated when they experience volition and choice while behaving; they are controlled when they experience pressure or coercion. Maintaining all of the recommended diabetes self-care behaviors is often overwhelming for patients as discussed earlier. An autonomous approach would be allowing them to choose which self-care behavior to focus first or more specifically, decisions within their exercise and eating plan that they believed would help with their blood glucose control and improving their health (Williams, et. al. 2005). The concept of controlled motivation would be following an eating plan or exercise schedule because their doctor or educator pressured them that these self-care behaviors were needed. "Individuals who perceive themselves to be competent when they are able to control important outcomes such as blood glucose levels and incompetent when they feel unable to control those outcomes" (Williams et al, 2004,

p.58). How the clinicians approach this discussion with patients may elicit different result with their patients.

The autonomous concerns discussed above are related to the experience of initiating behaviors, whereas perceived competence concerns the feelings about achieving the outcome (Williams, McGregor Zeldman, Feedman, Deci, 2004). If practitioners are autonomy supportive, patients will tend to be more autonomous and to feel more competent. Autonomy support refers to the extent to which providers elicit and acknowledge patients' perspectives, support patients' initiatives, offer choice about treatment options, and provide relevant information while minimizing pressure and control (Williams, et al. 2004). The practice of shared decision by nature of the term "shared" would include the provider's expertise on guiding treatment and discussion with their patient on preferences and choice in their care. In the literature, several studies have demonstrated that autonomy support by health care practitioners affect patients' motivation and health-relevant behaviors with regard to weight loss (Williams, Grow, Freedman, Ryan, & Deci, 1996), and medication adherence (Williams, Rodin, Ryan, Grolnick, & Deci, 1998). Furthermore, patient autonomy support, has been found to be a significant predictor of change in glycemic control over 12 months for patients with diabetes (Williams, Freedman, & Deci, 1998).

Similarly, the Social Cognitive Theory (Bandura, Self-efficacy, 1997) aligns with shared decision making and patient activation of lifelong self-care behaviors and chronic disease. It explains how people acquire and maintain certain behavioral patterns and can also be used for providing the basis for intervention strategies (Bandura 1997).

Social Cognitive theory has three components influencing each other the environment, people, and behavior (Glanz, Rimer, & Lewis, 2002). In Social Cognitive theory, the dynamic interaction of the person, the behavior, and the environment in which the behavior is performed is the concept referred to as reciprocal determinism (Glanz, et.al. 2002). The additional concepts within Social Cognitive theory include: Environmental factors which are social (family, friends and colleagues) and physical environment (actual location and perception of situation); Behavioral capability is the knowledge and skill to perform a given behavior. Expectations are the anticipatory outcomes of a behavior and Expectancies are the values that the individual places on a given outcome. Self-control is the personal regulation of goal directed behavior or performance. Observational learning is behavioral acquisition from watching others and reinforcement is the response given to a person's behavior that increases or decreases the likelihood of reoccurrence. Emotional coping is the strategies or tactics used by a person to deal with emotional stimuli. Finally, Self-Efficacy is the person's confidence in performing a particular behavior where the approach in successful behavioral change occurs in small steps (Glanz, et al., 2002).

These two theories provide a valuable understanding of the shared decision making encounter between the clinician/provider and the patient. The Self Determination theory (SDT) reveals the emphasis on the clinician providing autonomy support during these encounters to encourage patients to participate in their self-care. The Social Cognitive theory (SCT) provides the context around which each of these encounters will occur. It is a triad of factors affecting each patient throughout their diabetes management which includes

environmental, physical and behavioral capabilities. These capabilities may change over time and thus potentially key in each encounter

### **Research Questions and Hypothesis**

The healthcare encounter between clinicians and patients is an opportunity for patients to discuss their diabetes care management. Treatment environments that afford autonomy and support confidence are likely to enhance health outcomes (Ryan, 2008). Is this first phase of the shared decision making process key in helping patients maintain patient activation levels of self-care behaviors?

#### Research Questions

1. Is there a relationship between perceived healthcare provider autonomy support in shared decision making and patient activation levels?
2. Is there a relationship between gender and patient activation levels?
3. Is there a relationship between duration of Diabetes and Patient Activation levels?
4. Is there a relationship between previous Diabetes Education sessions and Patient Activation levels?
5. How well do these key diabetes care factors predict patient activation levels?

### Hypotheses

- Ho1: There is a relationship between perceived healthcare provider autonomy support in shared decision making and patient activation levels.
- Ho2: There is a relationship between gender and patient activation levels.
- Ho3: There is a relationship between duration of Diabetes and Patient Activation levels.
- Ho4: There a relationship between number of previous Diabetes Education sessions and Patient Activation levels.
- Ho5: Key diabetes care factors predict patient activation levels of shared decision making and activation of the self-care behaviors.



## Chapter II

### REVIEW OF THE LITERATURE

#### Definition of Terms

**Patient Centered Care:** The literature contains many references as to the terminology and definition of patient centered care (PCC) over the last 15 years. The terminology is part of an evolving healthcare environment with changing healthcare dynamics. The literature has sometimes aligned patient centered care with other terms such as patient centered, person centered, patient tailored, physician-patient alliance, physician patient trust, and physician patient communication, (Heisler, et al., 2003; Charles, Whel & Gafini, 1999; Shortus, Kemp, McKenzie & Harris, 2013). The Institute of Medicine (2001) clearly defined patient centered care as a partnership among practitioners, patients, and their families. According to the IOM, this patient centered partnership care includes decisions that respect patient preferences, needs and their values (IOM, 2001). This operational definition best reflects the basis of the research study.

**Shared Decision Making:** Shared decision making is a healthcare approach where clinicians and patients communicate together using the best available evidence. The patient and clinician deliberate about the possible attributes and consequences of options to arrive at informed preferences in deciding about the best action (Elwyn & Miron-Shatz, 2010).

Autonomy support: refers to taking the others perspective, encouraging initiation and exploration, providing choice and being responsive to individuals within a specific social context (Deci & Ryan, 2011)

Patient Activation: Patient activation is defined as an individual's ability and willingness to take on the role of managing their health and health care (Hibbard, et al., 2008).

Diabetes self-care behaviors: The AADE 7<sup>TM</sup> is considered the gold standard in diabetes self-care behaviors and includes healthy eating, being active, monitoring blood glucose, taking medication, problem solving, healthy coping and reducing risk (Haas, et al., 2013).

Hemoglobin A1c: The hemoglobin A1c test may be used to screen for and diagnose diabetes and prediabetes in adults. Hemoglobin A1c, also glycated hemoglobin or A1c, is formed in the blood when glucose attaches to hemoglobin. The higher the level of glucose in the blood, the more glycated hemoglobin is formed (AACC, 2015)

#### Importance of Diabetes Self Care Behaviors on Clinical Outcomes

As mentioned earlier, a patient's ability to maintain diabetes self-care behaviors is an integral part of their diabetes care. Diabetes education on self-care is reimbursed according to specific guidelines if provided by a formally recognized program from one of two national Accreditation organizations, the American Diabetes Association (ADA) or the American Association of Diabetes Educators (AADE), (Powers, et al., 2015). However,

regardless of formal program opportunities, the importance of diabetes self-care should be encouraged in all clinician and patient interactions based on evidence of improved clinical outcomes. For example, regular exercise is warranted to improve and/or maintain long-term glycemic control (Colberg, 2010). A single bout of exercise lowers circulating blood glucose concentrations and reduces the prevalence of hyperglycemic episodes throughout the subsequent day in type 2 diabetic patients (Manders et al., 2010; Praet et al. 2006). For those with type 1 diabetes, there are considerable data regarding health benefits of exercise including increased cardiovascular fitness, muscle fitness and improved insulin sensitivity (Colberg, 2013).

Similarly, the importance of nutrition in diabetes care on clinical outcomes is well documented. Helping patients with this self-care behavior can vary from encouraging healthful eating patterns to individualized medical nutrition therapy with A1c reductions of 0.3-1% for type 1 diabetes and 0.5-2% for type 2 diabetes (ADA, 2016).

Further, improvement in clinical outcomes has also been shown with other self-care behaviors like monitoring of blood sugar, adherence with medications, good problem-solving skills, healthy coping skills and risk-reduction behaviors. These self-care behaviors have been found to be positively correlated with good glycemic control, reduction of complications and improvement in quality of life (ADA, 2016). Despite these positive health outcomes maintaining self-care behaviors remains a challenge.

## Need for Improvement in Diabetes Self-care Behaviors

Results from two large observational studies provide perspective on how diabetes impacts daily life and highlights the current disconnect in improving diabetes self-care.

The Diabetes Attitudes, Wishes and Needs (DAWN) study was a multinational, cross sectional study of 5100 adult patients with diabetes and approximately 3100 health care providers interviewed face to face or via telephone (Peyrot et al.,2005). The aim of the study was to improve understanding of perceptions and attitudes of both patients and providers with regard to barriers in effective self-care. According to Peyrot (2005), patient-reported adherence to self-care recommendations is less than optimal; especially for lifestyle behaviors and providers are aware of this shortfall. In fact, providers noted a much lower level of estimated adherence than patients did for most self-care behaviors. This difference in perception can be a source of conflict in communication between patient and provider. Furthermore, the study showed that diabetes-related worries were common among patients, and providers generally recognized these worries but did not always feel comfortable in handling them or had inadequate resources (Peyrot, et al., 2005).

The second study DAWN2, looked to further understand the unmet needs of patients with diabetes, their families, and best practices to drive change and improve outcomes (Peyrot, et al 2013). Findings included that most people with diabetes are not actively engaged by their healthcare professionals to take control of their care though there is a need for improved self-management behaviors in diabetes. It was also noted that patients had difficulty in maintaining these behaviors but that they have the desire to

improve care. However, they don't often ask for support. In fact, many patients with diabetes confirmed that their healthcare teams were supportive but that key aspects of their care had not been discussed such as anxieties, diet, coping and the potential for individuals to take an active role in diabetes care (Peyrot, et al. 2013).

Healthcare professionals reported that about 60-90% of their patients need to improve self-management care, emphasizing only 10-40% being successful (Peyrot, et al. 2013). Results from both these studies unveiled the perspectives from both patients and healthcare providers and the importance of finding innovative efforts to improve self-care and provide the necessary global framework to transform study results into best practices, drive change and improve outcomes.

#### ADA 2012 Position Paper on Diabetes Management

In a 2012 position statement on management of hyperglycemia in type 2 diabetes by the American Diabetes Association (ADA) and European Association for the Study of diabetes (EASD) highlights the need for patient centered care as part of an overall framework in treating type 2 diabetes and related risk factors (Inzucchi, et al., 2012). The diabetes expert panel explained in this position paper that the current recommendations are less prescriptive and not as algorithmic as prior guidelines. Furthermore, these treatment recommendations should be considered within the context of the needs, preferences and tolerances of each patient and that individualization of treatment is the cornerstone of success (Inzucchi, et al., 2012). It was this paper that has brought more attention in the US

to the importance of patient centered care and in recent years and subsequent guidelines in diabetes care.

### Patient Centered Care

Patient centered care in the management of chronic disease is not a new concept yet a consistent application of the concept is still emerging. This lack of application may stem from inconsistency in how it is defined. Patient centered, person centered, patient focused, patient tailored, physician-patient alliance, physician patient –trust and physician patient communication are key terms associated with this model of care both here and abroad. (Heisler, et al., 2003; Gafini, Gafini, & Whelan, 1999; Shortus, Kemp, McKenzie, & Harris, 2011). Related descriptors include “tailoring patient treatment” and moving toward patient goals and humane care (Robinson, Callister, Berry, & Dearing, 2008). Central to all definition of patient centered care is that it represents change from the perceived inadequacies of traditional medical care and in particular the focus on the identification and treatment of the physical disease (biomedical model) and the domination of the doctor (Wagner, 2005).

Despite the famous words by Dr. Francis Weld Peabody in 1927, “The treatment of a disease may be entirely impersonal’ the care of a patient must be completely personal” (Peabody, 1927), most health professional training has been based on a medical model to treat acute health problems where the health professional was the authority responsible for diagnosis, treatment and outcomes patients experienced (Funnell, 2008). According to Robinson (2008), the physician manages the disease taking the responsibility for the

problem and care of the patients and this practice still remains prevalent in many health care practices. Lastly, underlying this disease focused management approach is the belief that patients have an obligation to follow the direction of their providers and that the beliefs of compliance outweigh the impact of these recommendations on the patient's quality of life (Funnell 2008).

One known consideration is that the disease management approach to health care practices and the patient's opinion on care is not always the same as their healthcare providers. A 1992 study, on 23 rural African Americans (aged 19-77), explored what compliance in health care meant to the patient. Contrary to their physician, the patients defined compliance in terms of apparent good health and sought treatment approaches that were manageable, livable and in their view effective. The patients developed systems of self-management that were suited to their lifestyles, beliefs, patterns and personal priorities in managing their chronic illness (Roberson, 1992).

An earlier definition of compliance is the extent to which a person's behavior in terms of taking medication, following diets, or executing life-style changes coincides with medical or health advice (Haynes & Sackett, 1979). However, many studies that focused on patient compliance (vs. concordance) have been shown to be ineffective in diabetes care (Rubin, 2002; Anderson & Funnell, 2000; Glasgow & Anderson, 1999). These and other related studies on the importance of the patient's input were soon followed by the Institute of Medicine (IOM) report on the the importance of more patient centric relationship (IOM, 2001).

In the Crossing the Quality Chasm: A New Health System for the 21st century report, the Institute of Medicine (IOM) emphasized that a healthcare system that achieves major gains in six areas would be far better at meeting patient needs. This public policy perspective included healthcare being “Safe, Effective, Patient-Centered, Timely, Efficient and equitable” (Institute of Medicine (IOM, 2001). Patient-centered was further defined as a partnership among practitioners, patients, and their families (when appropriate), that decisions respect patient preferences, needs, and values and that patient values guide all clinical decisions (IOM, 2001). The patient is the source of control as their perceived utility (usefulness of treatment) will impact adherence to treatment over time. Thus, patients should be given the necessary information and opportunity to exercise the degree of control they choose over health care decisions that affect them and the system able to accommodate preferences and encourage shared decision making (IOM 2001)

For patients living with diabetes who require lifelong self-management skills for positive health outcomes, enabling them to be responsible partners in their health care by promoting patient involvement and individualization of patient care is imperative (Little, et al., 2001). However, to implement patient centeredness in practice requires knowing which elements of patient centered care are the most important (Little, et al., 2001). One element of practice at the core of the patient centered care literature is the use of “shared decision making” (Chan, 2012; Gerteis, Edgman-Levitan, Dakey, & Delbanco, 1993; Funnell, 2014; Inzucchi, et al., 2012; Williams, Manias, & Walker, 2008; Montori, Gafni, & Charles, 2006; Reubin & Tinetti, 2012).



## Shared Decision Making

Shared decision making is a healthcare approach where clinicians and patients communicate together using the best available evidence when faced with the task of making decisions. In this approach, both the patient and clinician deliberate about the possible attributes and consequences of options to arrive at informed preferences in making a determination about the best action (Elwyn et al., 2010). Additionally, shared decision making enables the healthcare provider to identify possible barriers to adherence and offer potential solutions that incorporate the patient perspective (Harmon, Lefante, & Krousel-Wood, 2006).

Often, patients are concerned about issues related to symptom management, side effects, cost, quality of life and complexity of treatment which impacts their decision making and potentially limits their adherence (Vermeire, Hearnshaw, VanRoyen, & Denekens, 2001). Fostering a shared decision making process allows the patient to participate in the care discussion and with their provider choose a treatment that reflects his or her ability and propensity to adhere to treatment (Robinson, et al., 2008).

According to Bernabeo and Holmboe (2013), shared decision making is a competency domain that requires specific knowledge, skills and attitudes on the provider's part to engage a patient. The process allows providers to apply these competencies through a series of behaviors and activities with patients, such as assessing their preferences and uncovering important psychosocial factors that either facilitate or impede effective decision making (Bernabeo & Holmboe, 2013). The Charles model of shared decision making first described this as a sequential process in three phases (especially with regard to life

threatening illnesses), as information sharing, deliberation and decision making (Charles, Gafni, & Whelan, 1999).

The first phase in the Charles Model or information sharing is bidirectional allowing for patients (and their family members) and physicians (and other clinicians) to actively discuss care (diagnoses, symptoms, lifestyle issues and plan). The deliberation phase involves reviewing pros and cons of treatment considerations and patient preferences. The final phase of the model is the joint decision endeavor or shared decision making where patients and physicians agree on a care plan (Charles, Gafni, & Whelan, 1997; Charles et al., 1999). For patients with diabetes, this includes a discussion about implementation during which patient self-efficacy to perform self-management is included (Montori, Gafni & Charles, 2006).

As patient navigates the disease process they engage in decision making. Many factors inform patient's decisions such as preferences, cultural differences, age and socioeconomic status and impact their involvement in care (Popa-Lisseanu, et al., 2005; Street, Gordon, Krupat, Ward, & Kravitz, 2005; Tennstedt, 2000). Shared decision making does not exclude the promotion of evidence based medicine and instead incorporates the identification of pros and cons of treatment options, and value of patient preferences (Colyer & Kamath, 1999). Factors leading to patient's low engagement in their health care decisions include the perception that they lack knowledge, their perception that providers lack respect for their preferences and a lack of self-efficacy (Johnson, Meredith, Hickey, & Wells, 2006; Ngo-Metzger, Telfair, Sorkin, Weidmer, & Weech-Maldonado, 2006; Grembowski, et al., 1993).

The importance of patient centered care and emphasis on shared decision making for patients with diabetes is well supported. However, research in this area is still young and new instruments for the measurement of shared decision making are constantly being developed (Scholl et al., 2011). According to Scholl et al. (2011), in their review of shared decision making instruments, there are several challenges with regard to measurement of shared decision making. First there is the need to differentiate between elements or categories that surround the task of decision making which include decision antecedents, decision making process and decision outcomes. Scholl et al (2011) defined decision antecedents as the patient's role preference in their care and included several tools that considered autonomy preference, control preference, patient attitudes and beliefs and health opinions. The decision process was defined as both the deliberation and actual decision made with instruments that would assess both observed and perceived elements of the decision process. The final category or post decision phase was defined as tools to measure decision outcomes or for example, regret, satisfaction, or conflict with the decision made (Scholl et al., 2011).

In their review of SDM tools for each of these phases, Scholl and colleagues acknowledged that the range and complexity of evaluating shared decision making is challenging. Further, there is so far no primary measurement tool or standard outcome measure making the comparability of research results difficult (Scholl et al, 2011) In addition, tools vary from observational measures of the competence and performance of the clinician or patient to tools that measure the perception of the patient or clinician (Scholl 2011).

Several of the shared decision making tools reviewed by Scholl and colleagues do coincide with the same structure as the Charles model of the decision process, (i.e. information sharing, deliberation and decision making) discussed earlier. However, one key feature missing in these tools is observational scales focusing on patient's behavior in the medical encounter (Scholl et. al. 2011). The information sharing phase outlined by Charles appears to align in part the decision antecedent phase categorized by Scholl et al., (2011). Though, these first phase tools varied significantly from a patient's health beliefs to those that evaluated where the patient was in preparation to make a decision. Further, while listed in the decision antecedent category, the tools evaluated fell short of dynamic sharing of information sharing that precedes deliberation and actual decisions described by Charles (Charles et al., 1997). Do the patients even feel comfortable to participate in the encounter? Part of this information sharing phase is the integration of the patients, physicians and other healthcare clinicians' perception of the specific health care climate which further supports the patient's comfort level in sharing information during a medical interaction. According to Ryan, et al., treatment environments that afford autonomy and support confidence are likely to enhance health outcomes (Ryan, Patrick, Deci & William, 2008). Autonomy support refers to taking the others perspective, encouraging initiation and exploration, providing choice and being responsive to individuals within a specific social context (Deci & Ryan, 2011).

The literature reviewed supports the change from the traditional physician centered medical model of healthcare (Funnell, 2008; Robinson, 2008) to a patient centered care model. The process of shared decision making in healthcare incorporates the value of

patient preferences (Robinson, Callister, Berry, & Dearing, 2008; Coyler et al., 1999) in healthcare encounters and fosters a patient center model of healthcare. Thus, leading us to ask, “Will patients who perceive they have autonomy support via patient centered care practices vs controlled environments (physician centric) in their ongoing healthcare encounters have differences in activation of diabetes self-care behaviors?”

Making the suggestion to lose 20 pounds, exercise daily or regularly take diabetes medication to a patient who has little understanding of their chronic illness, progression of illness or need to play a role in managing it, is unlikely to result in the desired outcome. However, starting with appropriate goals that fit the patient’s level of activation, and working towards increasing level of activation in a step wise approach patients can achieve small successes and self-management confidence and skills (Bandura 1991; Battersby et al, 2003)

### Patient Activation

Patient activation is defined as an individual’s ability and willingness to take on the role of managing their health and health care (Hibbard, et al., 2008). This is particularly important in chronic disease where self-management skills are part of the overall treatment. The concept of activation focuses on skills and knowledge required for day-to-day management of one’s own health (Hibbard, et al., 2008). Positive changes in patient activation can lead to positive self-management behavior changes in patients with chronic conditions (Hibbard, Mahoney, Stock, & Tusler, 2007). Patient activation interventions have been developed for patients with cancer, diabetes, hypertension, obstetrical and

gynecological issues, and end-stage renal disease (Algeria, Sribney, Perez, Laderman, & Keefe, 2009).

Based on Pilling et al. such interventions work to increase patient involvement in personal healthcare through education and skill-building, often targeted toward patients initiating specific conversations with their clinicians, thereby promoting a bidirectional interaction between clinicians and patients (Pillings, et al., 2010) . Further, in a 2009 study on how people with different levels of activation self-manage their chronic disease, it was noted that that patients with lower level of activation tended to see successful self-management as compliance where those at higher levels of patient activation saw it as being in control and working in partnership with their health professionals (Dixon, Hibbard & Tussler, 2009).

Will an autonomy supported (Deci & Ryan, 2011) healthcare encounter of shared decision making be suffice to initiate, maintain or increase the level of patient activation in self-care behaviors such as exercise, healthy eating or medication adherence for patients with diabetes.

### The Health Care Climate Questionnaire (HCCQ)

Upon review of the literature several tools have been identified that would enable one to affectively address the research questions posed. The following section will provide a review of those tools and specifically speak to the constructs they measure, and their validity and reliability.

The Health Care Climate Questionnaire (HCCQ), (Williams, Grow, Freedman, Ryan & Deci, 1996) is the tool that will be used to measure patients perceived autonomy support. The tool is part of a family of questionnaires pertaining to the construct of autonomy support versus control to characterize the environment. Williams and all (1996) theorized that autonomy supportive social contexts (such as medical encounters) facilitate self-determined motivation, healthy development, and optimal functioning of individuals. The HCCQ 15-item Likert scale assesses participant's perceptions of the degree of autonomy support (vs. controllingness) of the relevant health care providers. It evaluates items such as "My physician tries to understand how I see things before suggesting a new way to do things" and "I feel my healthcare provider team has provided me with choices and options" (Williams et al. 1996). The patient's comfort level in engaging in this initial and bidirectional shared decision making to actively discuss care (diagnoses, symptoms, lifestyle issues and plan) will depend on how they perceive their environment. Perceived Autonomy support as measured by the healthcare Climate questionnaire may have no direct effect on a behavioral outcome such as frequency of exercise or eating well but may indirectly improve desire to improve self-care behaviors. Additionally, this type of "intervening" variable may help to refine more efficient interventions. (Patrick & Williams, 2012).

The questionnaire can be used to determine autonomy support of a specific physician or a group of healthcare providers. For this study, the researcher wanted to evaluate the perceived autonomy support from the "team of healthcare providers" and so the later format was used in the HCCQ instrument. The team of healthcare providers, a

physician, Certified Diabetes Educator (CDE) and/or Registered Nurse (RN) and/or Registered Dietitian Nutritionist (RDN) are all available at both the Geisinger Health System clinics (Endocrinology Clinic or Community Practice Service Line Clinics).

Scoring on both the 15-item version and the 6-item version are calculated by averaging the individual item scores. In the long version, used for this study, the score of one question needs to be reversed. Higher average scores represent a higher level of perceived autonomy support.

The original 15-item scale has been used in studies with weight loss and smoking cessation with a Cronbach alpha of .92 and .96 respectively. Factor analysis of the responses revealed a one factor solution measuring perceived autonomy support (Williams, et al. 1996).

#### Patient Activation Measure (PAM)

The Patient Activation Measure (PAM) is a valid, highly reliable unidimensional, probabilistic Guttman-like scale that reflects a model with four stages of patient activation. (Hibbard, Stockyard, Mahoney & Tusler, 2004). The four stages of activation include first, the patient believes an active role is important. Second, the patient has confidence and knowledge necessary to take action. This knowledge and confidence is not only about medication and lifestyle change but in talking to health care providers (knowing when to seek help, confidence in following through on recommendations, knowing the causes of the health condition and treatment options). The third stage is the taking action stage where the patient takes action including lifestyle changes, knowing how to prevent further problems



and handling symptoms on one's own in order to maintain and improve their health.

Finally, the fourth stage of patient activation is when the patient is able to stay the course even under stress. These patients are confident in maintaining lifestyle changes under stress, handling problems (not just symptoms) on their own at home and keeping their health problems from interfering with their life. (Hibbard et al, 2004).

Importantly the PAM includes a broad range of elements in activation including patient beliefs, knowledge, and skills and initiating and maintaining behaviors which is paramount in lifelong, diabetes self-care versus assessing these elements as single measures.

The Rasch rating scale model (Andrich, 1978; Wright & Stone, 1979) was used to analyze the original 22-item measure. Rasch measurement can be used to create interval-level data, unidimensional, probabilistic Guttman-like scales from ordinal data such as rating scale responses to survey questions (Rasch, 1960). The items have infit values (the degree to which the item falls on the same single, real number line as the rest of the items) between .76 and 1.32, well within the range required for a unidimensional measure (Hibbard, et al, 2004). Analysis of items Assessment of the 22-item PAM using stage three pilot survey national sample data showed a high level of reliability. Cronbach's alpha for the PAM is 0.91 and reliability statistics for those with and without chronic conditions are comparable (Hibbard et al, 2004).

To assess construct and criterion validity, the 22-item PAM variables believed to be conceptually related to activation were examined for their relationship to measured activation. Additionally, outcomes that are hypothesized to be a result of activation levels

were examined, such as health behaviors and health functioning. Validity was assessed for the sample as a whole and for those with specific chronic illnesses (Hibbard et al., 2004). The results indicated considerable evidence for the construct validity of PAM. Those with higher activation report significantly better health as measured by the SF8 ( $r = .38, p < .001$ ), and have significantly lower rates of doctor office visits, emergency room visits and hospital nights ( $r = -.07, p < .01$ ).

Those with higher activation are significantly more likely to exercise regularly, follow a low-fat diet, eat more fruits and vegetables, and not smoke. In addition, those with higher activation are significantly more likely to engage in consumeristic health behaviors, such as finding out about a new provider's qualifications. Self-management behaviors associated with specific conditions are also significantly associated with measured activation levels. For instance, diabetics with higher activation are more likely to keep a glucose journal, more-activated arthritics are more likely to exercise, and among those with high cholesterol, those with higher activation are more likely to follow a low-fat diet. Finally, those with higher activation indicate a lower degree of fatalism about their health", (Hibbard et al., 2004. p. 1021).

For this study, the shorter version or Patient Activation Measure, PAM13™ was be used to measure the outcome variable. It is designed: to assess patient knowledge, skill and confidence for self-management. Individual at early stages of activation would need interventions designed to increase knowledge about their condition and their treatments. Those patients at later stages would need interventions designed to increase their skills and confidence in the different self-management tasks.

The new 13 item measure was based on analysis aimed to reduce the number of items in the measure while maintaining adequate precision. The 13 items have a calibrated scale range from 38.6 to 53.0 (on a theoretical 0–100 point scale), compared with 38.3–54.5 for the 22 items. All of the infit and outfit statistics for the 13-item version of the PAM fall well within the 0.5–1.5 acceptable range and are essentially the same as in the 22-item version. The item reduction analysis resulted in the 13-item measure that has psychometric properties similar to the original 22-item version. (Hibbard et al., 2004, 2005)

The validity of this instrument is based on criterion validity (uses key criterion of self-described behavior) that was established using Cohen's kappa for measured activation. Each judge's classification were 90, .90 and 90, ( $p < 0.001$  for all three kappa's). There was little difference in the construct validity of the 13 item measure vs the 22 item measure. The Cronbach's alpha for internal consistency of instrument was 0.87 for the original 22 item instrument and the 13 item PAM score accounts for 92% of the variation in the 22 item version estimated activation. This verifies comparative reliability with minimal information lost in reduction process. (Hibbard et al., 2004, 2005).

Both of these instruments have been used in studies with diabetes populations (Health Care Climate Questionnaire: in Nicolucci et al., 2013; Rubak et al., 2009; Williams et al., 2007; Patient Activation Measure: in Monnier et al., 2006; Remmers et al., 2009; Rask et al., 2009).

## Discussion

The literature informs us that the US is facing an epidemic of diabetes care for years to come (Boyle J. , Thompson, Gregg, Barker, & Williamson, 2010; CDC, 2014).

Evidence is clear that diabetes self-care is essential in managing this chronic disease (ADA & AADE, 2013) that engaging in these self-care behaviors results in positive health outcomes.

A 2012 position statement on management of hyperglycemia in type 2 diabetes by the American Diabetes Association (ADA) and European Association for the Study of diabetes (EASD) highlights the need for patient centered care as part of an overall framework in treating type 2 diabetes and related risk factors (Inzucchi, et al., 2012). Patient centered care means providing care that is respectful of and responsive to individual patient preferences and ensuring that patient values guide all clinical decisions (IOM, 2001). Furthermore, this mode of healthcare delivery puts the patient at the forefront of all decision making and treatment (Asimakopoulou & Scambler 2013).

From the literature reviewed, shared decision making is at the core of patient centered care. However, there is limited literature in evaluating shared decision making and diabetes and there is no empirical evidence found at this time on the relationship between autonomy support in the shared decision making process and patient activation of self-care behaviors for patients with diabetes. Is it possible that an environment for shared decision making which allows the patient to be the expert on their lives (preferences) and the

clinician to provide the medical expertise in the medical encounter be a valuable strategy for activation and maintenance of diabetes self-care behaviors?

Therefore, the central purpose of this study was to determine if a relationship exists between autonomy support in shared decision making and patient activation of self-care behaviors in patients with diabetes. This was determined using the Healthcare Climate Questionnaire to measure patients perceived autonomy support in the healthcare environment and the Patient Activation measure (PAM13<sup>tm</sup>) to determine their level of patient activation in diabetes self-care behaviors.

### Chapter III

## METHODOLOGY

The proposed research design is non-experimental. There was no manipulation of the environment and no cause and effect established. The specific research approach used for the survey research is a mixed methods approach with concurrent data collection for both quantitative and qualitative analysis. The correlational research design was chosen because the study sought to determine if a relationship exists between the independent variables, (perceived autonomy support) and dependent variable (level of patient activation). This type of research is also used to make predictions including understanding the effect of predictor variables (perceived autonomy support, duration of diabetes, gender and diabetes education sessions) on patient activation level (Gliner, 2009).

Descriptive and comparative methodology was also included as part of the study methodology. For descriptive, there is no influence or interventions that affect the result; the results are just observed (Creswell, 2010). In this study individuals with diabetes were described by characteristics such as duration of diabetes, number of diabetes education sessions and gender). A comparative analysis is made between groups based on an attribute independent variable (Gliner, 2009). This study examined the difference between patient's perceived autonomy support and patient activation levels in the Endocrine Clinic versus the Community Practice Service Line Clinic.,

## Sample and Setting

Geisinger Health System is one of the nation's largest Integrated Health systems serving more than 3 million residents throughout 45 counties in Pennsylvania and southern New Jersey (Geisinger, 2016). Geisinger Health System agreed to coordinate the access to this population following Geisinger IRB approval in June 2016, in collaboration with Mary A Johnson MS RDN CDE BC-ADM, GHS Director of Diabetes Quality and Education.

The accessible population or sampling frame was adult patients with Diabetes at Geisinger Health System in PA that met the inclusion/exclusion criteria.

The sampling design is a nonprobability sample, specifically a convenience sample. A convenience sample may be used when random or systematic selection of participants is not feasible. Specifically, there is no way of estimating the probability that each participant has of being included in sample. Then the survey will be given to all those patients that meet the inclusion exclusion criteria. Additionally, there is no external selection; as all subjects who met criteria were being asked to complete survey rather than being chosen to participate (Gliner, et al., 2009).

Participants were recruited from either the Endocrine Specialty Clinic or Community Practice Service Line Clinics (CPSL) within the Geisinger Health system. The inclusion criteria included patients'  $\geq 18$  years of age who met the diagnostic criteria for diabetes for  $\geq 6$  months. These patients had been seen at least once previously in the Geisinger Medical Clinics so that they will be able to assess their healthcare providers. All

patients were able to read English and have access to a computer for the online survey. Those patients < 18 years of age with diabetes <6 months and no email/access to the internet to complete an online survey were excluded during the screening process. Additionally, if the patient had not yet had their first appointment at the Endocrine Specialty or Community Practice Service Line Clinic, they were not eligible to participate.

In order to calculate the sample size required, G\*Power (2011) software was utilized for a medium effect size of .30, a power level of .80 and alpha level of .05 (Faul et al., 2009), (Appendix E). For Correlation analysis in G\*Power 3.1, the study required a sample size of 82 individuals. For multiple regression analysis (Effect size  $f^2 = 0.15$  (MEDIUM);  $\alpha$  err prob = 0.05, Power (1- $\beta$  err prob= 0.80 and 4 predictors, the required sample size was 85 individuals.

Based upon survey literature of a 20% response rate (Creswell, 2013) as well as GHS Research team recommendation, a sample size of > 500 subjects were screened for inclusion in the study and added to the research distribution list. This is to account for a response rate of 20% and a required sample size of 85). Geisinger Health System (GHS) supported meeting the required sample size via screening by the data broker, for mass email distribution.



### Survey Instrumentation

The instrument used to measure the outcome variable is the Patient Activation Measure (PAM 13™), (Hibbard, 2005). The Patient Activation Measure is designed to assess patient knowledge, skill and confidence for self-management. An individual at early stages of activation would need interventions designed to increase knowledge about their condition and their treatments. Patients at later stages would need interventions designed to increase their skills and confidence in the different self-management tasks.

Criterion validity (using key criterion of self-described behavior) was established using Cohen's kappa for measured activation. Each judge's classification were .80, .90 and .90, ( $p < .001$  for all three kappa's). There was little difference in the construct validity of the 13-item measure vs the 22-item measure. The Cronbach's alpha for internal consistency of instrument was 0.87 for the original instrument and the 13 item PAM score accounts for 92% of the variation in the 22-item version estimated activation. This verifies comparative reliability with minimal information lost in reduction process.

The Healthcare Climate Questionnaire (HCCQ) was used to assess the patient's perception of the degree to which his doctor or team of health care providers is supportive of his autonomy. The instrument constructs exclusively cover perceived support for autonomy, competence, and relatedness. Autonomous motivation when they experience volition and choice while behaving in an environment and controlled motivation when they experience coercion or pressure. Ongoing autonomy support is related to perceived outcome; perceived outcome equals feelings about achieving outcome. the HCCQ can be

used to assess a patient's perception of the degree to which his doctor or team of health care providers is supportive of his autonomy. According to the analysis instructions, a patient's HCCQ score is calculated by taking the average of the individual item scores to yield a mean score between 1 and 7, after reversing the single reverse-scored item. Higher average scores represent a higher level of perceived autonomy support (Williams, Freedman & Ryan 1996; Deci & Ryan, 2014).

The validity of this instrument has previously been established in weight loss and smoking cessation studies using factor analysis which revealed a one-factor solution measuring perceived autonomy support. The HCCQ reliability has a Cronbach's alpha of 0.95 indicating strong internal consistency (Williams, et al., 1996).

To further understand the patient's perceived level of autonomy support two open ended questions were included in the survey as part of the qualitative data collection. This was two ascertain a more complete picture of themes important to the patients in their clinic interactions. These two questions followed the HCCQ instrument with the following instructions:

In order to help understand the importance of health care visits for individuals living with diabetes, please complete the following 2 questions below:

1. How would you describe your visits for Diabetes management with your team of health care providers?

2. What is the most important factor to you in your visits for Diabetes management with your team of health care providers

In this study the qualitative data is not being used to cross validate data but rather to capture different dimensions of the same phenomenon. Using content analysis approach from two open ended questions. the PI will be able to categorize open ended responses; see frequently-used words and phrases and develop inter-related themes.

In addition to the Health Care Climate Questionnaire (HCCQ) and Patient Active Measure (PAM) 13™), participants were asked to voluntarily complete demographic questions. This included age, gender, duration of diabetes, diabetes education session which were included as covariates in the study and two additional questions to denote education level and income range.

#### Procedure

The primary researcher contacted the Director of Diabetes Quality and Education of Geisinger Health System approximately one year before Geisinger Health System Internal Review Board submission to discuss the intended purpose of the study and to garnish support. In March 2016, additional guidance was provided on the necessary steps to conduct research at Geisinger Health System including conferences with relevant parties (GHS Research Coordinator, GHS Data Broker and GHS Research Distribution). After obtaining IRB approval from Geisinger Health and Seton Hall University, the following methodology was followed:

The primary researcher contacted the Geisinger Health System Biostatistics core data broker who would identify the population of interest. A separate teleconference was conducted to review the protocol and inclusion criteria for the study. Since there were two clinic groups of interests, the data broker was instructed to include 50% of subjects from the Endocrine clinic and 50% from Community Practice Service Line clinic meeting the study inclusion criteria. The survey distribution list of was as an Excel spread sheet directly to the Office of Communication (for mass email distribution) at Geisinger per protocol requirements. The primary researcher did not receive any identifiable data on Geisinger Health System patients.

The participant email/letter was sent directly by the primary researcher to the Geisinger Office of Communication (for mass email). The participant email/letter included the confidential link to complete the survey in Survey Monkey®. used. The email content clearly stated the voluntary nature of participation including no penalty for not participating. The participant email/letter also included a statement regarding anonymity for all participants who chose to participate in all or part of the survey completion. Patients receiving the email made a decision to participate in the research study or not (see Procedure flow chart). The PI had an option to request a reminder email to the same potential participants from the electronic mailing list to remind them of the study, and encourage their participation approximately four weeks from the initial email distribution as needed. The survey was open for 8 weeks. No additional reminder email was sent to participants.

## Data Analysis

A mixed method design was used analyze the data. To assess the relationship between autonomy support in shared decision making on patient activation level inferential statistics will be used. Specifically, a Pearson's correlation(s) was conducted for each independent variable autonomy support, gender, duration of diabetes and previous diabetes education on the outcome variable on the level of patient activation. A multiple linear regression analysis will follow this to obtain predictor information about the model as a whole and the relative contribution of each of the variables on patient activation, (outcome variable). For all the statistics analyses an alpha level (0.05),  $\beta$  level (0.2) with a corresponding power of 80% using SPSS Software version 21

For qualitative data, a content analysis approach was used for the two open ended questions to further understand the patients perceived level of autonomy support as indicated by their Healthcare Climate questionnaire score. This allowed the researcher to examine the topics contained within the messages to develop themes (Frey, Botan & Kreps, 2007). In this study the qualitative data is not being used to cross validate data but rather to capture different dimensions of the same phenomenon. Using the text Analysis process within survey monkey, the Co-PI will be able to categorize open ended responses; see frequently-used words and phrases. These two open ended questions were evaluated for all those who completed this section and the sample n calculated to reflect any missing data. The transcribed data was reported across surveys, followed by inter-coder agreement. (two researchers trained in qualitative research independently coded like statements & established potential themes).

## Chapter IV

### RESULTS

#### **Introduction**

This purpose of this study was to investigate the patient's perception of autonomy support in shared decision making on level of patient activation as measured by the Healthcare Climate Questionnaire (HCCQ) and Patient Activation Measure (PAM) 13™ respectively.

The analysis consisted of three major components. First a quantitative analysis of the **Exploring Autonomy support and Patient Activation level survey** data was completed which looked at demographic characteristics of the respondents. This included relevant sample statistics and meaningful graphic display of central tendency, dispersion, and shape of the distribution.

The second component of the quantitative analysis concentrated on answering the five research questions about the relationship of the individual predictor variables. perceived autonomy support, gender, duration of diabetes, diabetes education sessions and outcome variable, Patient Activation level. Lastly, a multiple regression model on the predictability of these key factors together on patient activation levels.

The final component reviewed the qualitative data using a content analysis approach to establish triangulation. Analysis of two open ended questions was completed to further the understanding of the relationship between perceived autonomy support in shared decision making and patient activation levels.

### Characteristics of Sample

Five hundred and three (503) patients with diabetes were distributed the electronic survey per Geisinger Health System protocol and a 20% return rate was achieved. Approximately 50% of the sample were patients seen in the Endocrine clinic and the other 50% were seen in the Community Practice Service Line (CPSL) medical clinics. One hundred and one patients completed the survey, with Endocrine patients at 54 percent and CPSL patients at 47 percent (Table 1). No surveys were excluded from the analysis (Table 1). Post Hoc G\*power analysis for the inferential statistics revealed actual power of .88 for the sample obtained (Appendix E).

Table 1  
*Medical Clinic*

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 1 ENDOCRINE CLINIC	54	53.5	53.5	53.5
2 OTHER - CPSL CLINIC	47	46.5	46.5	100.0
Total	101	100.0	100.0	

### Quantitative Findings: Descriptive Statistics

**Respondent's Gender:** More females than males took this survey. This is slightly higher than the current prevalence of diabetes regarding gender (CDC, 2016).

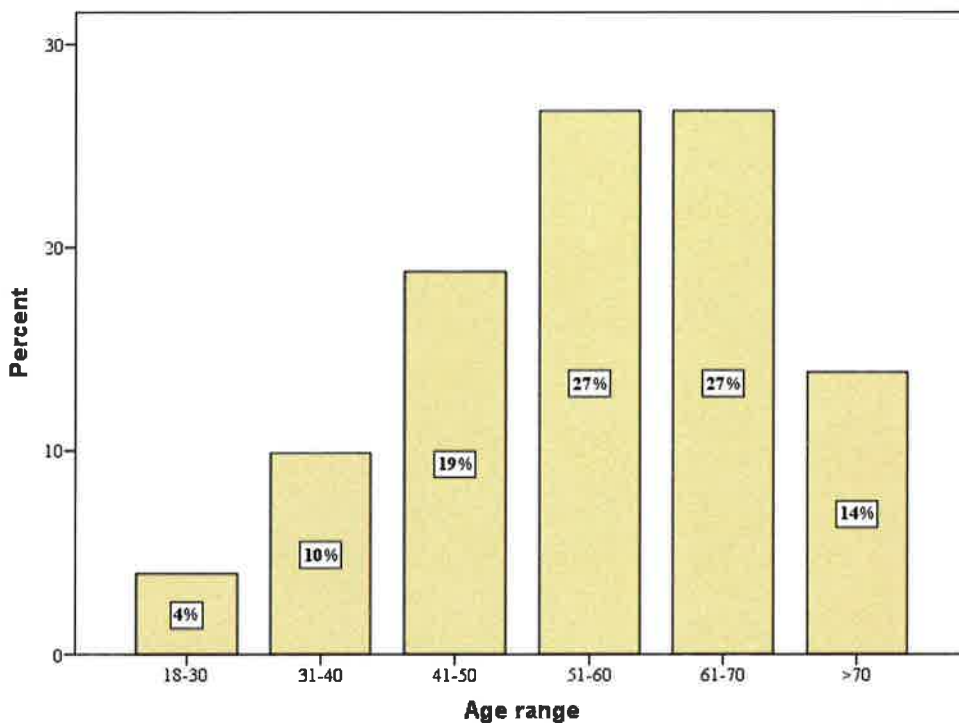
**Table 2**  
*Frequencies and Percentages of Respondents Per Gender*

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 0 MALE	40	39.6	39.6	39.6
1 FEMALE	61	60.4	60.4	100.0
Total	101	100.0	100.0	

**Age of Respondents.** Most respondents were over age 50 with equal percentages in the 51-60 and 61-70 range. All age groups were represented with an equal number of respondents between less than 40 years of age and greater than 70 years of age.

The percentage of respondents with diabetes in the 41-50 age was 19 percent.





*Figure 1.* Bar graph illustrating age of respondents in 10-year increments.

Most respondents (54%) were between 51-70 years of age. The results on age for this study are above the 2012 CDC data on prevalence of diabetes in seniors over age 65 noted at 25.9 percent (CDC, 2012).

**Education Level of Respondents.** Survey results included representation from all education levels by Geisinger Health system patients. One third of respondents had a high school education while 45% had either an associate's or bachelors level college education. There were 16 percent of patients with a graduate or doctoral degree and only 6 patients

who selected “other” for formal education level.

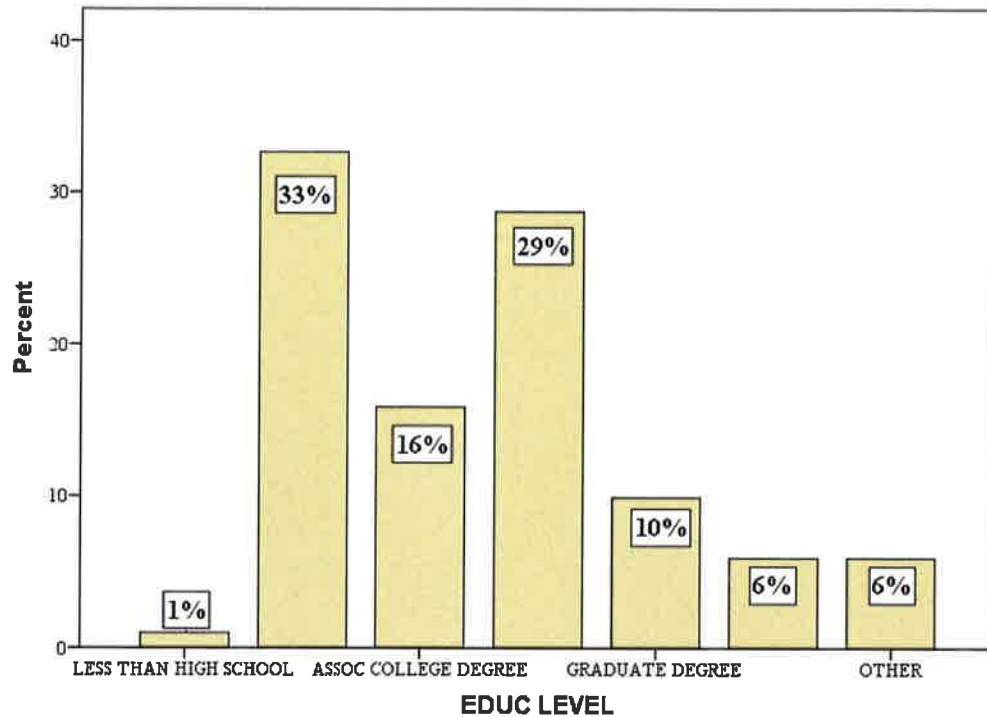
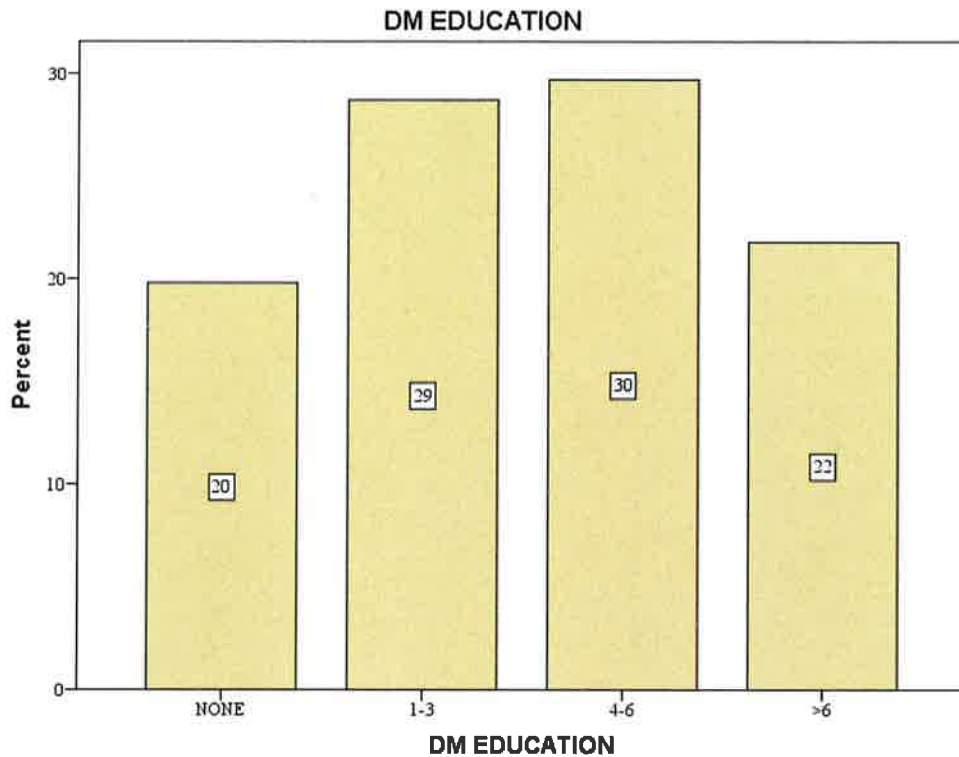


Figure 2. Bar graph illustrating the level of formal education for survey respondents.

Table 3

*Diabetes Education*

	Frequency	Percent	Valid Percent	Cumulative Percent
0 NONE	20	19.8	19.8	19.8
1 1-3	29	28.7	28.7	48.5
Valid 2 4-6	30	29.7	29.7	78.2
3 >6	22	21.8	21.8	100.0
Total	101	100.0	100.0	



*Figure 3.* A bar graph displaying the number of Diabetes Education Sessions for Respondents

**Duration of Diabetes of Respondents:** As shown in the table 3 below, survey participants had a mean duration of diabetes of 13 years and standard deviation of 9.1 years. The most frequent response to the question “how many years have you had diabetes” was 10 years while with a range between one and forty years with diabetes.

Table 4

<i>Duration of Diabetes</i>		
N	Valid	101
	Missing	0
Mean		13.05
Median		11.00
Mode		10
Std. Deviation		9.090
Minimum		1
Maximum		40

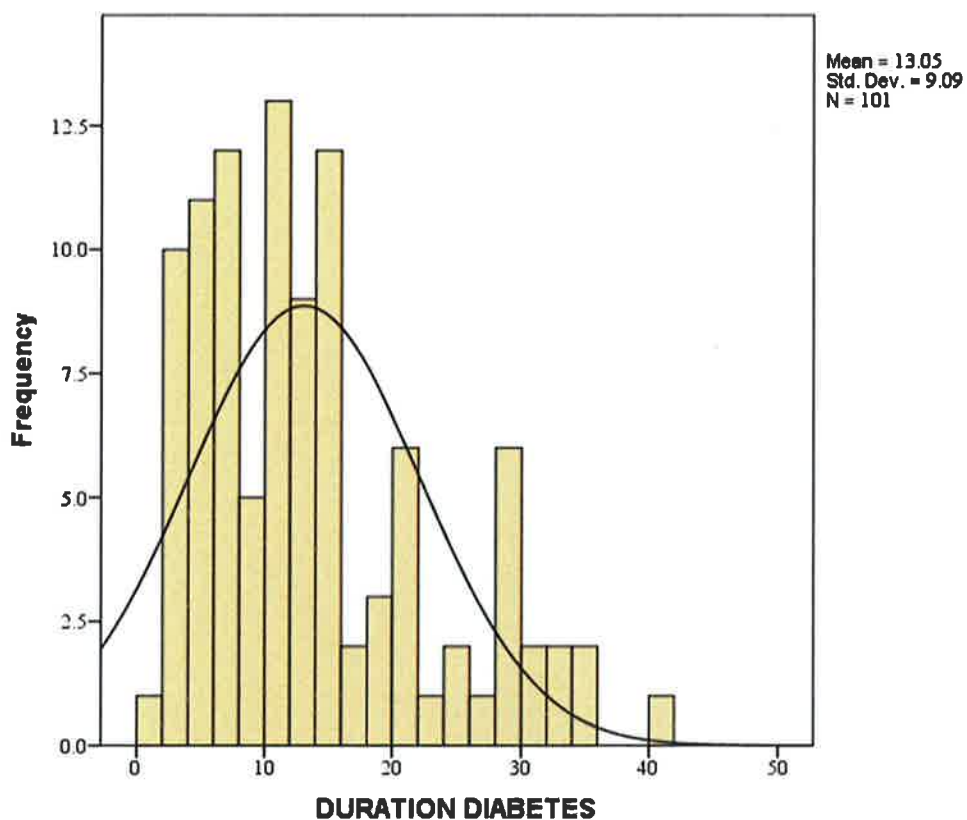
Table 5

*Tests of Normality*

	Kolmogorov-Smirnov <sup>a</sup>			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Duration of Diabetes	.138	101	.000	.912	101	.000

a. Lilliefors Significance Correction

The distribution is not normal based on the Kolmogorov-Smirnov (K-S) test and the Sharapiro-Wilk (S-W) test  $p < 0.05$  meaning that there is deviation from normal distribution. However, K-S and S-W will fail when you have a large sample size (N.=100). Although the test for normality is significant, the sample mean is normally distributed based on the Central Limit Theorem (Field, 2009).



*Figure 4.* A histogram displaying respondents' duration of diabetes in years.

Most respondents (54%) were between 51-70 years of age. The results on age for this study are just above the 2012 CDC data on prevalence of diabetes in seniors over age 65 noted at 25.9 percent (CDC, 2012).

**Perceived Autonomy Support of Respondents:** Table 5 below displays the mean respondent score of perceived autonomy support as measured by the Health Care Climate Questionnaire. The mean score of 86.8 is out of a total possible score of 105 points. The minimum score received was 55 points and the maximum score received was the full 105 points. Like duration of diabetes, the test for normality for this variable (perceived autonomy support) was significant at  $p < 0.05$ . The Central Limit Theorem states that when samples are large (above 30), the sampling distribution will take the shape of a normal distribution. (Field, 2009).

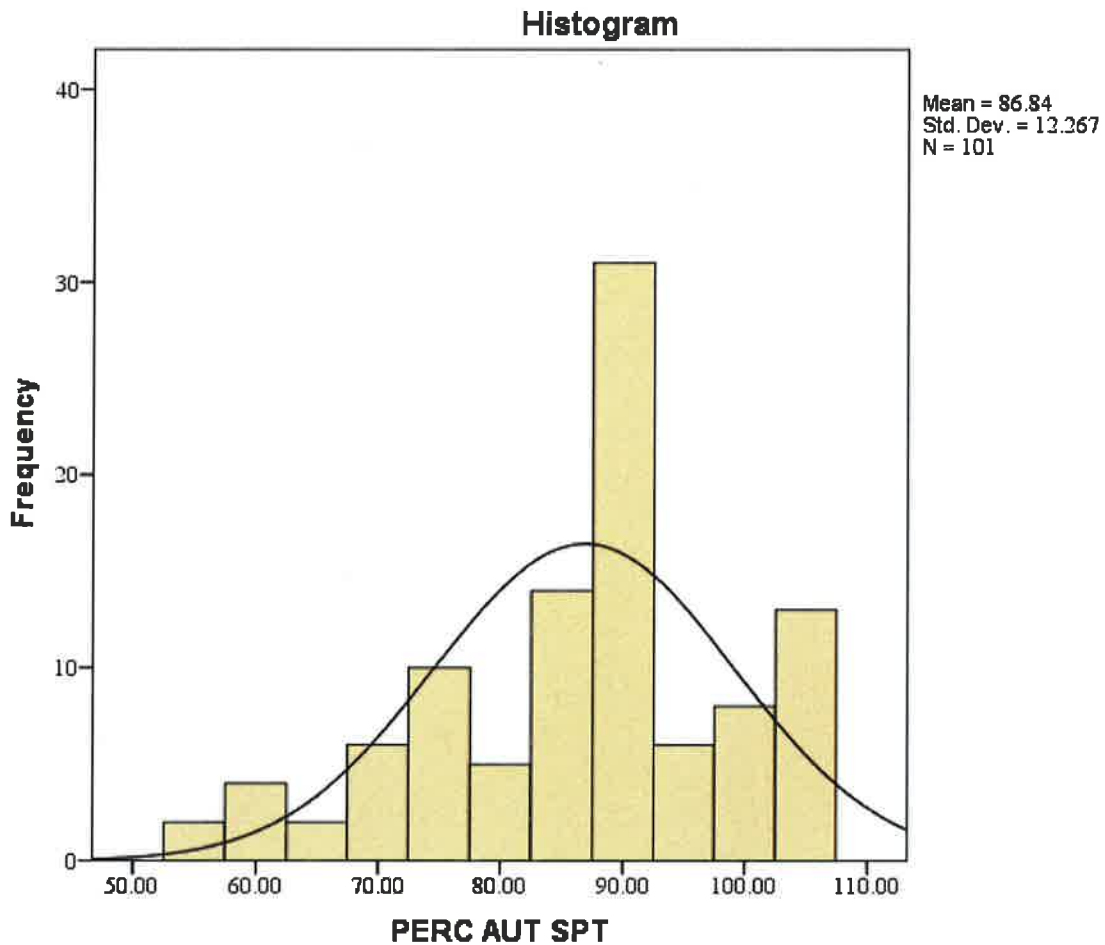
Table 6  
*Perceived Autonomy Support*

N	Valid	101
	Missing	0
Mean		86.84
Median		89.00
Mode		91.00
Std. Deviation		12.26
Minimum		55.00
Maximum		105.00

Table 7

	Kolmogorov-Smirnov <sup>a</sup>			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Perceived Autonomy Support	.133	101	.000	.944	101	.000

a. Lilliefors Significance Correction



*Figure 5.* A histogram on frequency of perceived autonomy support scores.

**Quantitative Findings:** The second part of the analysis was to answer specific research questions regarding relationships and predictability of the variables on patient activation levels (scores). A Post Hoc G\*Power Analysis with an actual sample size of N=101 revealed actual power of .88 for the correlation analysis.

**Ho1.** There is a relationship between perceived healthcare provider autonomy support in shared decision making and patient activation levels (score)?

Table 8  
*Relationship between Perceived Autonomy Support and Patient Activation Score*

		Perceived Autonomy Support	Patient Activation Score
Perceived Autonomy Support	Pearson Correlation	1	.479**
	Sig. (2-tailed)		.000
	N	101	101
Patient Activation Score	Pearson Correlation	.479**	1
	Sig. (2-tailed)	.000	
	N	101	101

\*\* . Correlation is significant at the 0.01 level (2-tailed).

The relationship between perceived autonomy support (as measured by the Health Care Climate Questionnaire-HCCQ) and Patient Activation Scores (as measured by the Patient Activation Measure (PAM) 13™) was investigated using Pearson correlation. There was a moderate, positive correlation between the two variables,  $(r(2) = .479, p < .01, n=101)$  meaning as perceived autonomy support increases so does the patient activation score.



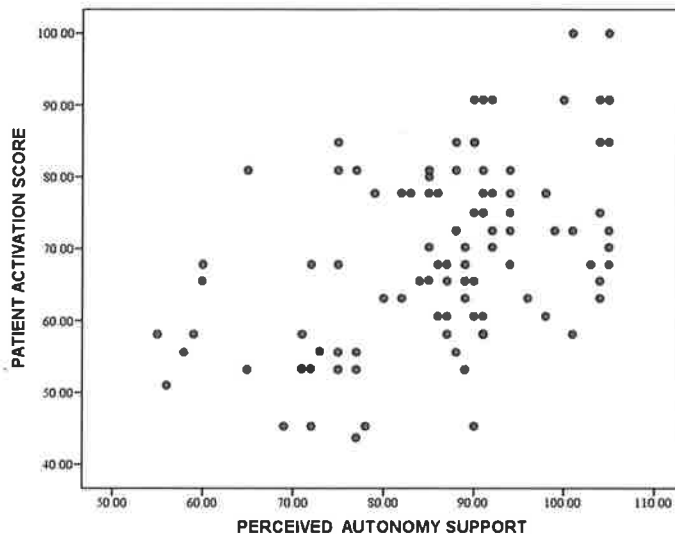


Figure 6. Scatterplot indicating positive correlation between Perceive Autonomy support and Patient Activation Score.

**H<sub>o2</sub>**. There is a relationship between gender and patient activation level (score)?

Table 9

*Relationship between Gender and Patient Activation Score*

		GENDER	PAT ACT SCORE
Spearman's rho	GENDER	Correlation Coefficient	1.000
		Sig. (2-tailed)	.241*
		N	101
			101
	PAT ACT SCORE	Correlation Coefficient	.241*
		Sig. (2-tailed)	.015
		N	101
			101

\* Correlation is significant at the 0.05 level (2-tailed).

Table 9 displays the relationship between Gender and Patient Activation Score

using the Spearman's rho non-parametric correlation test. There was a weak, positive

correlation found between the two variables that was significant, ( $\rho(2) = .241$   $p < .05$ ),  $n=101$  meaning that a patient's gender was not related to the patient activation scores in this sample.

**Ho3.** There is a relationship between Duration of Diabetes and Patient Activation levels (score).

The relationship between Duration of Diabetes and Patient Activation score was assessed using Pearson correlation (table 10 below). There was a weak, negative correlation found between the two variables, ( $r(2) = -.212$ ,  $p < .05$ ) meaning that those with longer duration of diabetes had lower levels of patient activation scores.

Table 10

*Relationship between Duration of Diabetes and Patient Activation Score*

		PAT ACT SCORE	DURATION DIABETES
PAT ACT SCORE	Pearson	1	-.212*
	Correlation		
	Sig. (2-tailed)		.034
	N	101	101
DURATION of DIABETES (DOD)	Pearson	-.212*	1
	Correlation		
	Sig. (2-tailed)	.034	
	N	101	101

\*. Correlation is significant at the 0.05 level (2-tailed).

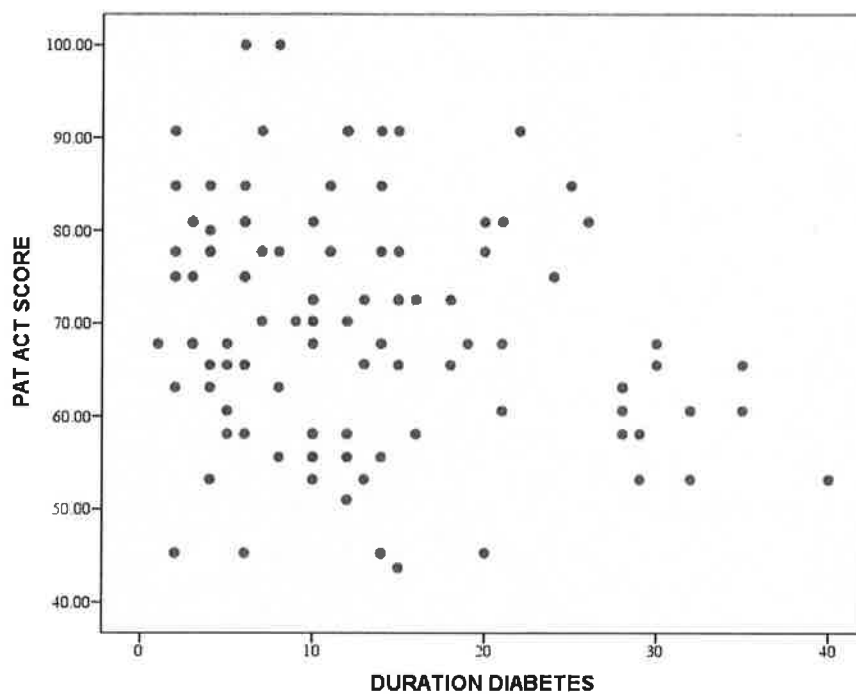


Figure 7. Scatterplot of the negative relationship between DOD and Patient Activation.

**Ho4.** There a relationship between number of previous Diabetes Education sessions and Patient Activation level (score).

Table 11

*Relationship between Diabetes Education Sessions & Patient Activation Score*

		DM EDUCATION	PAT ACT SCORE
<b>Spearman's rho</b>	<b>DM EDUCATION</b>	<b>Correlation Coefficient</b>	<b>1.000</b>
		<b>Sig. (2-tailed)</b>	<b>.015</b>
		<b>N</b>	<b>101</b>
	<b>PAT ACT SCORE</b>	<b>Correlation Coefficient</b>	<b>.015</b>
	<b>Sig. (2-tailed)</b>	<b>.878</b>	
	<b>N</b>	<b>101</b>	

Finally, the relationship between the number of previous diabetes education sessions and patient activation (as measured by the Patient Activation Measure (PAM) 13™) was investigated using Spearman's rho correlation. A very weak, positive correlation that was not significant was found, ( $\rho(2) = .015$   $p > .05$ ). The number of diabetes education sessions is not related to patient activation score.

**Ho5.** Key diabetes care factors predict patient activation levels (score).

To determine if a model could be used to predict patient activation level from four independent variables, (perceived autonomy support, gender, duration of diabetes and the number of diabetes education sessions), a multiple regression analysis was completed. Prior to the testing a review of assumptions for this statistical technique was performed. This includes adequate sample size, review of outliers, multicollinearity of independent variables, and normality, linearity homoscedasticity and independence of the residuals.

First a post hoc G\*Power Analysis with a sample size of  $N=101$  revealed an actual power of .88 for the multiple regression analysis (Appendix E). This is aligned with Stevens (1996) who recommends "fifteen subjects per predictor" are needed for a reliable equation in social science research (Stevens, (p.72).

There were no extreme outliers (indicated with asterisk) for the Perceived Autonomy support or duration of diabetes as shown by the box plot for each variable in Figure 8 and Figure 9 below. Normal distribution of the response or outcome variable, patient activation score is shown in Table 12 as noted by non-significant Shapiro-Wilk result.

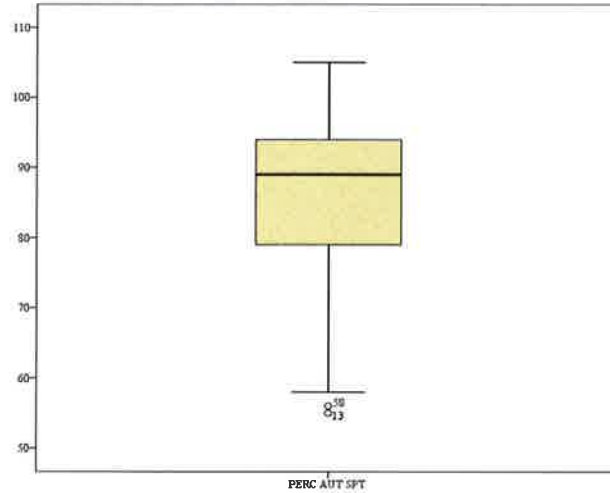


Figure 8. Box plot on predictor variable Perceived Autonomy Support

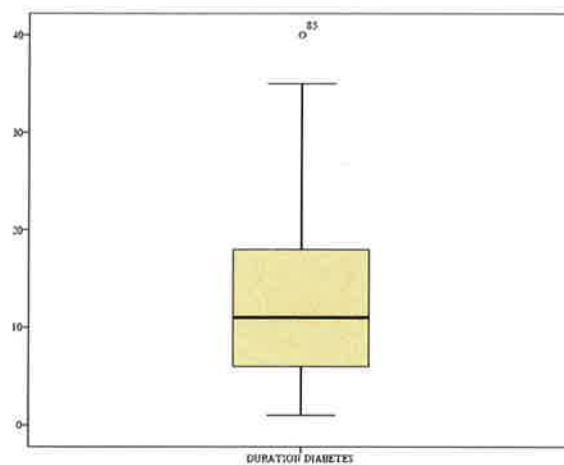


Figure 9. Box plot on predictor variable Duration of Diabetes

Table 12

*Tests of Normality Response Variable*

	Kolmogorov-Smirnov <sup>a</sup>			Shapiro-Wilk (S-W)		
	Statistic	df	Sig.	Statistic	df	Sig.
PAT ACT SCORE	.069	101	.200*	.983	101	.229

Multicollinearity was assessed using the collinearity diagnostics within SPSS analysis as part of the multiple regression procedure. Both the Tolerance (not less than .10) and Variance inflation factor (VIF value not above 10) assumptions were met as shown in Table 13. Tolerance is an indicator of how much influence one independent variable has on all other independent variables. VIF measures how much the variance of the estimated regression coefficients is inflated as compared to when the predictors are not linear related (Tabachnick & Fidell, 2007).

**Table 13**  
**Coefficients<sup>a</sup>**

Model	Unstandardized		Standardized	t	Sig.	95.0% Confidence			Correlations			Collinearity	
	Coefficients		Coefficients			Interval for B			Zero- order	Partial	Part	Tolerance	VIF
	B	Std. Error	Beta			Lower Bound	Upper Bound	order					
(Constant)	30.20	8.11		3.721	.000	14.08	46.31						
PERC AUT SPT	.47	.09	.46	5.098	.000	.288	.656	.479	.462	.444	.939	1.065	
GENDER	1.60	2.45	.06	.654	.515	-3.27	6.48	.191	.067	.057	.831	1.203	
1 DURATION													
DIABETES	-.26	.13	-.19	-1.982	.050	-.53	.000	-.212	-.198	-.172	.820	1.219	
DM													
EDUCATION	.50	1.13	.04	.446	.656	-1.75	2.76	.038	.046	.039	.858	1.166	

a. Dependent Variable: PAT ACT SCORE

A normal probability plot (P-P) of the regression standardized residual and scatterplot were inspected to assess the remaining assumptions (normality, linearity, homoscedasticity, and independence of residuals). The points on the P-P plot lie in a reasonable straight line meaning no major deviations of from normality (Figure 10). Additionally, the variance around the regression line is similar for all predictor variables.

The scatterplot of standardized residuals is roughly rectangularly distributed with most of the scores concentrated in the center (Figure 11).

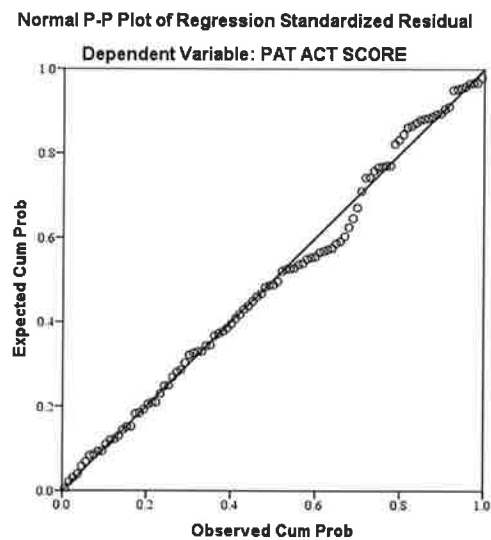


Figure 10. Normal Probability Plot of the Regression Standardized Residual.

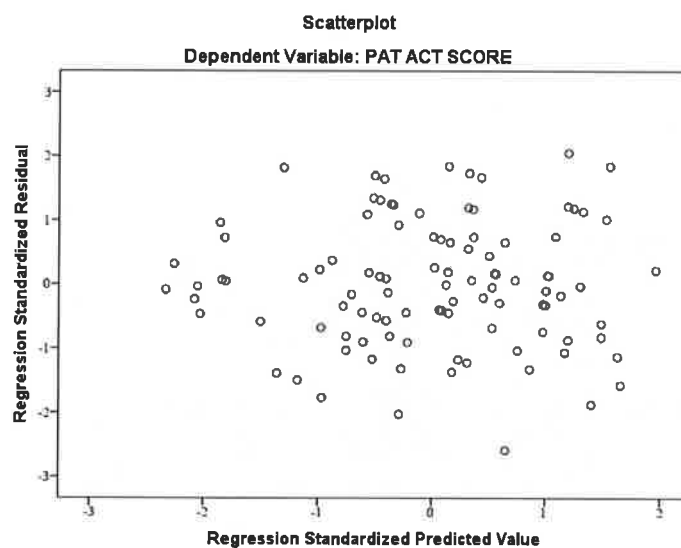


Figure 11. Scatterplot of Standardized Residuals for model.

To determine if key diabetes care factors predict patient activation levels (score) the Model summary was evaluated. As displayed in Table 14, the R Square for the model is .273 meaning that the model explains 27.3% of the variance of the patient activation score.

Table 14

*Model Summary<sup>b</sup>*

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.522 <sup>a</sup>	.273	.243	11.01598

a. Predictors: (Constant), DM EDUCATION, PERC AUT SPT, GENDER, DURATION DIABETES

b. Dependent Variable: PAT ACT SCORE

Table 15

*ANOVA<sup>a</sup>*

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	4374.301	4	1093.575	9.012	.000 <sup>b</sup>
	Residual	11649.766	96	121.352		
	Total	16024.068	100			

a. Dependent Variable: PAT ACT SCORE

b. Predictors: (Constant), DM EDUCATION, PERC AUT SPT, GENDER, DURATION DIABETES

The ANOVA table provides the statistical significance of the result meaning it is testing the null hypothesis that multiple R in the population equals 0. The result was statistically significant,  $F(4,96) = 9.01$ ,  $p < .0005$  as highlighted in the ANOVA model (Table 15) and the null hypothesis is rejected. The coefficients that made a statistically



significant contribution to the model, are perceived autonomy support and duration of diabetes as seen in Table 13 presented earlier.

Table 16

*Patient Activation Level*

	Frequency	Percent	Valid Percent	Cumulative Percent
	1	5	5.0	5.0
	2	7	6.9	11.9
Valid	3	44	43.6	55.4
	4	45	44.6	100.0
Total	101	100.0	100.0	

The frequency of respondents representing each patient activation level is shown in table 16 with 88% in in the higher levels (level 3 or 4).

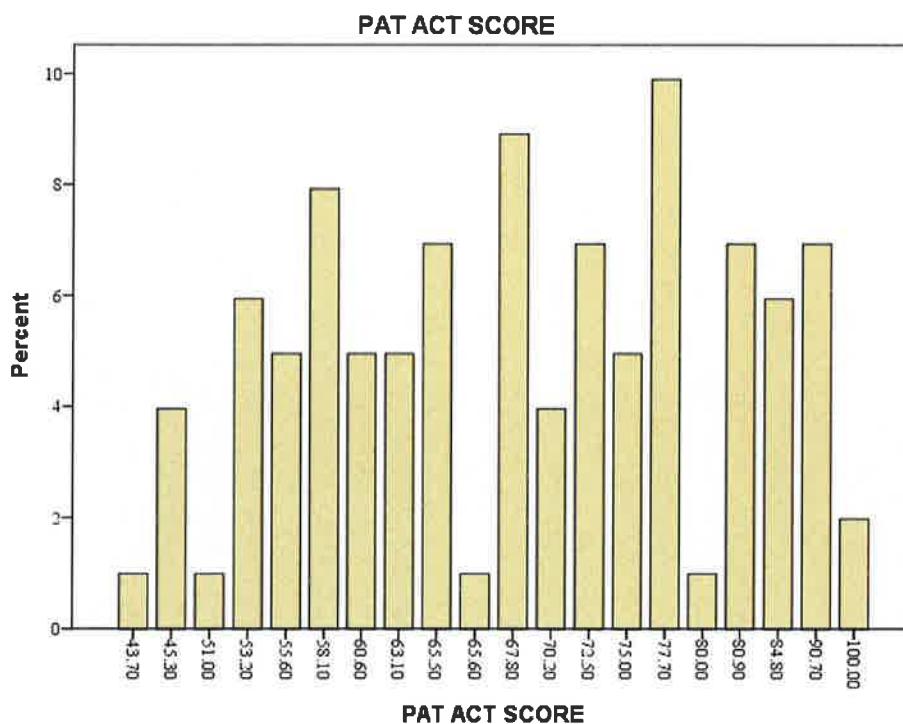


Figure 12. Histogram of Respondent Patient Activation scores.

## Qualitative Findings

For the qualitative research findings, a content analysis approach as outlined by Frey, Botan & Kreps was completed (2007). Qualitative responses were included from 96 respondents for question one and 97 respondents for question two from the survey sample of N=101.

- Open Ended Question #1

How would you describe your visits for diabetes management with your team of health care providers?

- Open Ended Question #2

What is the most important factor to you in your visits for diabetes management with your health care providers?

The text from two open ended questions were examined for diabetes topics within the messages so that common themes could be generated. All data was transcribed as reported and inter-coder agreement between two researchers was completed. There were five themes established in “describing their visit for diabetes management” in question one shown in Table 17. The second table 18, highlights the six themes established for the “most important factor” to the patient in their visit with their team of health care providers.

Table 17

<b>Open Ended Question #1</b>	<b>How would you <u>describe</u> your visits for diabetes management with your team of health care providers?</b>			<b>Interrater Reliability IRR= .968</b>
				<b>97%</b>
<b>Informative</b>	<b>Time Limitations</b>	<b>Caring</b>	<b>Feels Valued</b>	<b>Negative Experience</b>
“opportunity for information”	“Short”	Used the word “care”	“Listens to me”	Negative emotions expressed such as “frustrated, overwhelmed, too nervous, guilty”.
“Valuable information”	“Not enough time”	“Nice”	“Understands me”	“I wish they would...” “Always the same...”
“Information provided efficiently”	“Limited time”	“Helpful”	“Respects me”	“Always rushed”
<b>Percentage of respondents providing comments for each of the identified themes</b>				
<b>38.5%</b>	<b>16.7%</b>	<b>13.5%</b>	<b>17.7%</b>	<b>13.5%</b>

Interrater reliability between researchers for themes established for statements made in response to question one was 97% as shown in table 17 above.

## Chapter V

### DISCUSSION & CONCLUSION

#### Discussion

The literature informs us that the US is facing an epidemic of diabetes care for years to come. According to the CDC, current diabetes prevalence is at 29 million with another 86 million Americans with pre-diabetes (2012). The epidemic numbers are compounded by the complexity of required, daily self-care behaviors by patients to improve their clinical outcomes. However, despite the importance of diabetes self-care behaviors, there remains a disconnect in patient's not able to follow these behaviors and not asking for any help from their healthcare professionals, (Peyrot et al., 2013).

Individualized patient care is part of the American Diabetes Association position statement (2013) and the 2017 Standards of Care for patients with diabetes (ADA, 2017). Shared decision making in patient centered care allows for individualized care in a dynamic exchange of information between a patient and healthcare professional (Charles et al., 1999). This dynamic exchange is supported the central tenet of the Self Determination Theory which states the quality of the environment influences the motivation, performance, and well-being of the individuals within them (Deci & Ryan, 1985). Initiating and maintaining patient activation levels is also supported by the Social Cognitive theory and reciprocal determinism or the dynamic interaction of the person, the behavior, and the environment in which the behavior is performed (Bandura, 1977).

Autonomy support refers to taking the others perspective, encouraging initiation and exploration, providing choice and being responsive to individuals within a specific social context (Deci & Ryan, 2011). The importance of an autonomy supported environment in the shared decision process on patient activation levels was investigated as an approach to help understand and ultimately improve the patient's ability to maintain these behaviors.

This exploratory research was conducted in collaboration with Geisinger Health System (GHS) in Pennsylvania. The online survey was screened and distributed to patients with diabetes meeting protocol requirements from both the GHS Endocrine clinic and their Community Practice Service Line Clinic. Both clinic patients were reasonably represented with approximately 54% from the Endocrine clinic and 46% from the CPSL clinic. All patients with diabetes within the Geisinger Health System have access to diabetes education regardless of the type or location of the clinic where they are seen.

Initial descriptive statistics were performed on each of the variables to determine the frequency and dispersion of the data obtained. Assessment of perceived autonomy support as measured by the Healthcare questionnaire (HCCQ) was higher than anticipated with a mean score of 87 out of a possible 105 points and approximately one third of participants scoring 90 or above (figure 5). Similarly, patient activation levels were higher than expected. Patient activation is defined as an individual's ability and willingness to take on the role of managing their health and health care (Hibbard, et al., 2008).

The distribution of the Patient Activation Measure (PAM) 13™ scores included 5% at level one, 7% at level two and 88% achieving a level three or four. As discussed earlier,

individuals at early stages of activation would need interventions designed to increase knowledge about their condition and their treatments. Patients at later stages would need interventions designed to increase their skills and confidence in the different self-management tasks. Thus, most respondents to this research survey scored high in their perceived autonomy support as well as their patient activation level.

Most survey respondents were over age 60 which is typical with current statistics on type 2 diabetes (CDC, 2012) but what was not expected was an equally high percentage in both the 51-60 and 61- 70 age group and approximately 20% between 40-50 years of age. Earlier diagnosis of type two diabetes in this health system may have contributed to the higher frequency of patients in this age group. Further, the survey was open to patients with type one or type two diabetes. This question was not included in the demographic section of the survey and there may have been more younger patients with Type 1 diabetes between 40-50.

Gender was reported as 40% male and 60% female for those completing the survey which provides a reasonable contribution for gender as a predictor but the total sample size did not allow for analysis of perceived autonomy support on patient activation for both male and female groups. Of the total survey respondents, approximately one third had high school education, 45% had college education and 16 % had graduate or doctoral degrees.

Mean duration of diabetes in the sample at 13 years exceeded the researchers expected range of < 10 years. The sample included a wide range of duration of diabetes with a minimum and maximum range of 1-40 years allowing for potentially more varied

responses. Based on a sample size (N=101) further assessment of the relationship of duration of diabetes on the outcome variable was completed and will be discussed as in the following section.

The frequency of diabetes education session was higher than expected with 81% having had diabetes education sessions (approximately 30% for 1-3 sessions and 4-6 sessions, 22% greater than 6 sessions and only 22% not having diabetes education sessions). This was the only predictor variable that I thought might have some multicollinearity with the patients perceived level of autonomy support which did not occur.

In total four predictor variables were reviewed in relation to patient activation levels including perceived Autonomy support, gender, duration of diabetes and number of diabetes education sessions. Results of this study did show that perceived autonomy support in shared decision making was moderately related to their patient activation level. Specifically, as perceived autonomy support increases so does the patient activation level. Perceived autonomy support explained about 23% of the shared variance alone.

Further analysis of the relationship between gender on Patient activation levels was weak and differences between male and female participants could not be analyzed with the current sample size. However, in a recent study evaluating gender and patient activation levels, no difference between men and women with type 2 diabetes treated in primary care in 3 regions in the Netherlands (Hendriks, 2016).

The duration of diabetes and patient activation level was a weak and negative relationship ( $r(2) = 1.212, p < .05$ ) in our current study indicating that those with longer duration of diabetes had slightly lower patient activation scores. Hendriks (2016) included duration of diabetes on patient activation in two models with approximately 1500 patients and concluded that it was not associated with the PAM score (p. 3).

There was no relationship ( $r(2) = .015, p > .05$ ) between the number of diabetes education session and patient activation levels. This finding was unexpected because all patients within the Geisinger Health system have access to diabetes educators as part of their healthcare team and most patients had multiple education sessions.

In the linear multiple regression model including all four predictor variables on patient activation, the amount of variance explained increased to 27% and slightly higher than that explained by perceived autonomy support on patient activation scores alone. The only two variables of significance in the model were duration of diabetes and perceived autonomy support.

### Qualitative Themes

The qualitative findings further helped explain the quantitative results and potential factors contributing to level of perceived autonomy support as well as patient activation levels. Themes were established around the two-open ended questions. The first on how they would describe their healthcare visit for diabetes management and the second on the



most important factor to them in their visit for diabetes management with their healthcare providers.

Both questions had responses analogous with perceive autonomy support and feeling comfortable in their healthcare encounter for diabetes care. In describing their healthcare visit, 31% of the patient responding in themes related to “feeling valued, understood and respected with caring professionals”. Thirty eight percent of patients described their visit as informative. The final group of patients described their visits around time limitations (17%) meaning they desired “more time” in their visit while approximately 13% expressed some negative emotions such as being nervous, anxious, or not respected in their visits.

The second question queried the patient on the most important factors to them in diabetes management with their healthcare professional team. Of the six themes generated three were aligned with an autonomy supported environment by 72% of respondents. Patients acknowledged that “feeling supported, having “their questions answered and medication concerns addressed as two key themes and providing encouragement with guidance as third theme where the quality of the environment was a key factor. Understanding their glycemic control and learning accounted for another 27% of comments. There were only two negative comments reported for this question around the need for follow up communication from their health providers.

**Study Limitations:** The following discussion details the limitations of the research study.

**Self-reported findings.** The limitations of the study are the same for all self-reported surveys. Respondents may have a subject bias associated with a self-administered test.

**Sampling.** Inability to send multiple mass email distributions based on Geisinger Health system requirements to further increase the sample size.

**Generalizability.** The results of this study are only generalizable to the Geisinger Health System from which the sample of diabetes patients was obtained.

**Exploratory Research.** This exploratory research does not intend to offer final and conclusive solutions to the problem identified but rather a greater understanding of the research topic as a basis for additional research.

**Future Research Directions:**

This study was undertaken because there was limited literature on how to help patients maintain patient activation levels and no known literature on the association of perceived autonomy support in shared decision on patient activation levels in patients with diabetes.

The first consideration is to expand this research topic to include a larger sample size to evaluate relationships and differences between multiple groups such as rural and urban clinics, Integrated delivery systems, type 1 vs type 2 diabetes patients and male and female patients. A more complex analysis with perceived autonomy support on multiple outcome measures such as A1c, BMI or Lipids in addition to patient activation levels would provide a greater understanding of the “quality of the environment” and improving a patient’s ability to maintain self-care behaviors.

Another direction is exploratory research on differences between Patients and their healthcare providers on the level of perceived autonomy in healthcare interactions. Perceived autonomy support as the outcome or responder variable.

To assist Geisinger colleagues with an intervention designed to incorporate autonomy supported healthcare interactions vs usual care in clinic visits for patients with diabetes.

- Follow up at 3, 6 and 12 months on Patient Activation levels
- Correlation with clinical outcomes such as A1c, BMI, weight

## **Conclusion**

This study provides an understanding of perceived autonomy support in shared decision making and patient activation levels for diabetes self-care behaviors. The greatest responsibility in diabetes care lies with the patient in daily self-care behaviors

Helping patients to initiate and maintain these self-care behaviors must remain a priority now and in the future for an estimated 29.1 million Americans with diabetes and the 86 million Americans living with pre-diabetes. Autonomy support refers to the extent to which providers elicit and acknowledge patient's perspectives and support patient initiatives.

Greater than 25 % of patients suggest that perceived autonomy support in shared decision making does enhance patient activation levels (scores). Multiple themes including feeling valued, supported, and encouraged in the healthcare interaction were dominant areas of importance based on qualitative analysis of survey responders. These themes are analogous with an autonomy supported environment. In healthcare practices, we can increase patients Perceived Autonomy Support and thus increase Patient Activation levels in patients with diabetes

## References

- Abbott, M. L., & McKinney, J. (2013). *Understanding and applying research design* John Wiley & Sons.
- Alegría, M., Sribney, W., Perez, D., Laderman, M., & Keefe, K. (2009). The role of patient activation on patient–provider communication and quality of care for US and foreign born latino patients. *Journal of General Internal Medicine*, 24(3), 534-541.
- American Association of Clinical Chemistry – AACC (2016).  
<http://clinchem.aaccjnls.org/content/47/11/1985.short>
- American Association of Diabetes Educators. (2009). Special considerations in the management and education of older persons with diabetes. *The Diabetes Educator*, 35(3 suppl), 60S-63S.
- American Diabetes Association. (2014). Standards of medical care in Diabetes—2014. diabetes care 2014; 37 (suppl. 1): S14–S80 Diagnosis and classification of diabetes mellitus. diabetes care 2014; 37 (suppl. 1): S81–S90. *Diabetes Care*, 37(3), 887-887.
- American Diabetes Association. (2015). 4. foundations of care: Education, nutrition, physical activity, smoking cessation, psychosocial care, and immunization. *Diabetes Care*, 38(Supplement 1), S20-S30. doi:10.2337/dc15-S007

- American Diabetes Association. (2016). Standards of medical care in diabetes-2016: 39 (Supplement 1).
- American Diabetes Association. (2017). Standards of Medical Care in Diabetes—2017: Summary of Revisions. *Diabetes Care*, 40(Supplement 1), S4-S5.
- Anderson, R. M., & Funnell, M. M. (2000). Compliance and adherence are dysfunctional concepts in diabetes care. *The Diabetes Educator*, 26(4), 597-604.
- Andrich, D. (1978). A rating formulation for ordered response categories. *Psychometrika*, 43(4), 561-573.
- Ash, S., Reeves, M. M., Yeo, S., Morrison, G., Carey, D., & Capra, S. (2003). Effect of intensive dietetic interventions on weight and glycemic control in overweight men with type II diabetes: A randomized trial. *International Journal of Obesity*, 27(7), 797-802.
- Asimakopoulou, K., & Scambler, S. (2013). The role of information and choice in patient-centred care in diabetes: A hierarchy of patient-centredness. *European Diabetes Nursing*, 10(2), 58-62.
- Bandura, A. (1978). Reflections on self-efficacy. *Advances in Behaviour Research and Therapy*, 1(4), 237-269.
- Bandura, A. (1991). Social cognitive theory of self-regulation. *Organizational Behavior and Human Decision Processes*, 50(2), 248-287.

Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York: Freeman.

Bandura, A., & McClelland, D. C. (1977). Social learning theory.

Battersby, M. W., Ask, A., Reece, M. M., Markwick, M. J., & Collins, J. P. (2003). The partners in health scale: The development and psychometric properties of a generic assessment scale for chronic condition self-management. *Australian Journal of Primary Health, 9*(3), 41-52.

Bernabeo, E., & Holmboe, E. S. (2013). Patients, providers, and systems need to acquire a specific set of competencies to achieve truly patient-centered care. *Health Affairs (Project Hope), 32*(2), 250-258. doi:10.1377/hlthaff.2012.1120 [doi]

Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002). Patient self-management of chronic disease in primary care. *Jama, 288*(19), 2469-2475.

Bodenheimer, T., Wagner, E. H., & Grumbach, K. (2002). Improving primary care for patients with chronic illness: The chronic care model, part 2. *Jama, 288*(15), 1909-1914.

Boulé, N., Kenny, G., Haddad, E., Wells, G., & Sigal, R. (2003). Meta-analysis of the effect of structured exercise training on cardiorespiratory fitness in type 2 diabetes mellitus. *Diabetologia, 46*(8), 1071-1081.

Boyle, J. P., Thompson, T. J., Gregg, E. W., Barker, L. E., & Williamson, D. F. (2010). Projection of the year 2050 burden of diabetes in the US adult population: Dynamic modeling of incidence, mortality, and prediabetes prevalence. *Popul Health Metr, 8*(1), 29.

- Centers for Disease Control and Prevention. (2014). National diabetes statistics report: Estimates of diabetes and its burden in the united states, 2014. *Atlanta, GA: US Department of Health and Human Services,*
- Chan, A.CDC: 1 in 3 Americans will have diabetes by 2050. (2012). (2012)  
<http://www.nbcnews.com/id/39798848/ns/health-diabetes/t/cdc-americans-will-have-diabetes/>, retrieved April 9, 2012
- Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Social Science & Medicine, 44*(5), 681-692.
- Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician–patient encounter: Revisiting the shared treatment decision-making model. *Social Science & Medicine, 49*(5), 651-661.
- Colberg, S., & Riddell, M. (2013). Physical activity: Regulation of glucose metabolism, clinical management strategies, and weight control.
- Colberg, S. R., Sigal, R. J., Fernhall, B., Regensteiner, J. G., Blissmer, B. J., Rubin, R. R., . . . American Diabetes Association. (2010). Exercise and type 2 diabetes: The american college of sports medicine and the american diabetes association: Joint position statement. *Diabetes Care, 33*(12), e147-67. doi:10.2337/dc10-9990 [doi]



- Colyer, H., & Kamath, P. (1999). Evidence-based practice. A philosophical and political analysis: Some matters for consideration by professional practitioners. *Journal of Advanced Nursing*, 29(1), 188-193.
- Cooper, H. C., Booth, K., & Gill, G. (2003). Patients' perspectives on diabetes health care education. *Health Education Research*, 18(2), 191-206.
- Cornell, S., McCoy, J., Letassy, N.m Haas, L., Boren, S., Fitzner, K., Fisher, E. et al., (2011). Taking medication in diabetes self- management: Issues and recommendations for reducing barriers. *American Journal Pharmacy Benefits*, 3(5), 263-271.
- Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approaches* Sage publications.
- Creswell, J. W. (2010). Mapping the developing landscape of mixed methods research. SAGE handbook of mixed methods in social & behavioral research, 2, 45-68.
- DAFNE Study Group. (2002). Training in flexible, intensive insulin management to enable dietary freedom in people with type 1 diabetes: Dose adjustment for normal eating (DAFNE) randomised controlled trial. *BMJ (Clinical Research Ed.)*, 325(7367), 746.
- Deci, E. L., & Ryan, R. M. (1985). *Intrinsic motivation and self-determination in human behavior* Springer Science & Business Media.
- Deci, E. L., & Ryan, R. M. (2011). Self-determination theory. *Handbook of Theories of Social Psychology*, 1, 416-433.

Deci, L., & Ryan, R. (2014). Healthcare Climate Questionnaire,

<http://selfdeterminationtheory.org/questionnaires/>

Diabetes Prevention Program Research Group. (2015). HbA1c as a predictor of diabetes and as an outcome in the diabetes prevention program: A randomized clinical trial. *Diabetes Care*, 38(1), 51-58. doi:10.2337/dc14-0886 [doi]

Dixon, A., Hibbard, J., & Tusler, M. (2009). How do people with different levels of activation self-manage their chronic conditions? *The Patient: Patient-Centered Outcomes Research*, 2(4), 257-268.

Elwyn, G., & Miron-Shatz, T. (2010). Deliberation before determination: the definition and evaluation of good decision making. *Health Expectations*, 13(2), 139-147.

Faul, F., Erdfelder, E., Buchner, A., & Lang, A. (2009). Statistical power analyses using G\*power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods*, 41(4), 1149-1160.

Field, A. (2009). *Discovering statistics using SPSS*. Sage publications.

Frey, L., Botan, C., & Friedman, P. G. (81). and Kreps G (1999) Investigating Communication: An Introduction to Research Methods.

Funnell, M. M., & Anderson, R. M. (2000). The problem with compliance in diabetes. *JAMA*, 284(13), 1709-1709.

- Funnell, M. M., & Anderson, R. M. (2008). Influencing self-management: From compliance to collaboration. *Type 2 diabetes mellitus* (pp. 455-466) Springer.
- Funnell, M., Anderson, R., & Piatt, G. (2014). Empowerment, engagement, and shared decisions in the real world of clinical practice. *Consultant*, *54*(5), 358-362.
- Garcia Popa-Lisseanu, M. G., Greisinger, A., Richardson, M., O'Malley, K. J., Janssen, N. M., Marcus, D. M., . . . Suarez-Almazor, M. E. (2005). Determinants of treatment adherence in ethnically diverse, economically disadvantaged patients with rheumatic disease. *The Journal of Rheumatology*, *32*(5), 913-919. doi:0315162X-32-913 [pii]
- Geiss, L. S., Wang, J., Cheng, Y. J., Thompson, T. J., Barker, L., Li, Y., . . . Gregg, E. W. (2014). Prevalence and incidence trends for diagnosed diabetes among adults aged 20 to 79 years, united states, 1980-2012. *Jama*, *312*(12), 1218-1226.
- Gerteis, M. (1993). *Through the patient's eyes: Understanding and promoting patient-centered care* Jossey-Bass Inc Pub.
- Gerteis, M., Edgman-Levitan, S., Daley, J., & Delbanco, T. L. (1997). Through the patient's eyes: Understanding and promoting patient-centered care. *Journal for Healthcare Quality*, *19*(3), 43.
- Glanz, K., Rimer, B., & Lewis, F. (2002). The theory of reasoned action and the theory of planned behaviour. *Health Behaviour and Health Edification: Theory Research and Practices*, 67-98.

- Glanz, K., Rimer, B. K., & Viswanath, K. (2008). *Health behavior and health education: Theory, research, and practice* John Wiley & Sons.
- Glasgow, R. E., & Anderson, R. M. (1999). In diabetes care, moving from compliance to adherence is not enough. *Diabetes care*, 22(12), 2090
- Gliner, J. A., Morgan, G. A., & Leech, N. L. (2011). *Research methods in applied settings: An integrated approach to design and analysis* Routledge.
- Goldhaber-Fiebert, J. D., Goldhaber-Fiebert, S. N., Tristan, M. L., & Nathan, D. M. (2003). Randomized controlled community-based nutrition and exercise intervention improves glycemia and cardiovascular risk factors in type 2 diabetic patients in rural costa rica. *Diabetes Care*, 26(1), 24-29.
- Golin, C. E., DiMatteo, M. R., & Gelberg, L. (1996). The role of patient participation in the doctor visit. implications for adherence to diabetes care. *Diabetes Care*, 19(10), 1153-1164.
- Grembowski, D., Patrick, D., Diehr, P., Durham, M., Beresford, S., Kay, E., & Hecht, J. (1993). Self-efficacy and health behavior among older adults. *Journal of Health and Social Behavior*, 89-104.
- Haas, L., Maryniuk, M., Beck, J., Cox, C. E., Duker, P., Edwards, L., . . . 2012 Standards Revision Task Force. (2013). National standards for diabetes self-management education and support. *Diabetes Care*, 36 Suppl 1, S100-8. doi:10.2337/dc13-S100 [doi]

- Harmon, G., Lefante, J., & Krousel-Wood, M. (2006). Overcoming barriers: The role of providers in improving patient adherence to antihypertensive medications. *Current Opinion in Cardiology*, 21(4), 310-315. doi:10.1097/01.hco.0000231400.10104.e2 [doi]
- Harris, M. (1995). Diabetes in America. In M. Harris (Ed.), *National diabetes data group (US); national institute of diabetes; digestive; kidney diseases (US)* (2nd Edition ed.,). NIH Publication No. 95-1468: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases.
- Haynes, R. B., & Sackett, D. L. (1979). *Compliance in health care* Johns Hopkins University Press.
- Heister, M., Vijan, S., Anderson, R. M., Ubel, P. A., Bernstein, S. J., & Hofer, T. P. (2003). When do patients and their physicians agree on diabetes treatment goals and strategies, and what difference does it make? *Journal of General Internal Medicine*, 18(11), 893-902.
- Hendriks, S. H., Hartog, L. C., Groenier, K. H., Maas, A. H., van Hateren, K. J., Kleefstra, N., & Bilo, H. J. (2016). Patient activation in type 2 diabetes: Does it differ between men and women? *Journal of Diabetes Research*, 2016
- Hibbard, J. H., Mahoney, E. R., Stockard, J., & Tusler, M. (2005). Development and testing of a short form of the patient activation measure. *Health Services Research*, 40(6p1), 1918-1930.

- Hibbard, J. H., Mahoney, E. R., Stockard, R., & Tusler, M. (2007). Do increases in patient activation result in improved self-management behaviors? *Health services research*, 42(4), 1443-1463.
- Hibbard, J. H., & Cunningham, P. J. (2008). How engaged are consumers in their health and health care, and why does it matter? *Res Brief*, 8, 1-9.
- Hibbard, J. H., Greene, J., Becker, E. R., Roblin, D., Painter, M. W., Perez, D. J., . . . Tusler, M. (2008). Racial/ethnic disparities and consumer activation in health. *Health Affairs (Project Hope)*, 27(5), 1442-1453. doi:10.1377/hlthaff.27.5.1442
- Hibbard, J. H., Stockard, J., Mahoney, E. R., & Tusler, M. (2004). Development of the patient activation measure (PAM): Conceptualizing and measuring activation in patients and consumers. *Health Services Research*, 39(4p1), 1005-1026.
- Institute for the Future. (2000). *Health and health care 2010*. (). San Francisco, CA.: Jossey-Bass Publishers.
- Institute of Medicine (US). Committee on Quality of Health Care in America. (2001). *Crossing the quality chasm: A new health system for the 21st century* National Academy Press.
- Inzucchi, S. E., Bergenstal, R. M., Buse, J. B., Diamant, M., Ferrannini, E., Nauck, M., . . . European Association for the Study of Diabetes (EASD). (2012). Management of hyperglycemia in type 2 diabetes: A patient-centered approach: Position statement of the

american diabetes association (ADA) and the european association for the study of diabetes (EASD). *Diabetes Care*, 35(6), 1364-1379. doi:10.2337/dc12-0413 [doi]

Johnson, M. D., Meredith, L. S., Hickey, S. C., & Wells, K. B. (2006). Influence of patient preference and primary care clinician proclivity for watchful waiting on receipt of depression treatment. *General Hospital Psychiatry*, 28(5), 379-386.

Krapek, K., King, K., Warren, S. S., George, K. G., Caputo, D. A., Mihelich, K., . . . Lubowski, T. J. (2004). Medication adherence and associated hemoglobin A1c in type 2 diabetes. *The Annals of Pharmacotherapy*, 38(9), 1357-1362. doi:10.1345/aph.1D612 [doi]

Kulkarni, K., Castle, G., Gregory, R., Holmes, A., Leontos, C., Powers, M., . . . Wylie-Rosett, J. (1998). The diabetes care and education dietetic practice group. nutrition practice guidelines for type 1 diabetes mellitus positively affect dietitian practices and patient outcomes. *J Am Diet Assoc*, 98, 62-70.

Leslie, R., Kolb, H., Schloot, N., Buzzetti, R., Mauricio, D., De Leiva, A., . . . Hadden, D. (2008). Diabetes classification: Grey zones, sound and smoke: Action LADA 1. *Diabetes/metabolism Research and Reviews*, 24(7), 511-519.

Little, P., Everitt, H., Williamson, I., Warner, G., Moore, M., Gould, C., . . . Payne, S. (2001). Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations. *BMJ (Clinical Research Ed.)*, 323(7318), 908-911.

- Miller, C. K., Edwards, L., Kissling, G., & Sanville, L. (2002). Nutrition education improves metabolic outcomes among older adults with diabetes mellitus: Results from a randomized controlled trial. *Preventive Medicine, 34*(2), 252-259.
- Monnier, L., Mas, E., Ginet, C., Michel, F., Villon, L., Cristol, J., & Colette, C. (2006). Activation of oxidative stress by acute glucose fluctuations compared with sustained chronic hyperglycemia in patients with type 2 diabetes. *Jama, 295*(14), 1681-1687.
- Montori, V. M., Gafni, A., & Charles, C. (2006). A shared treatment decision-making approach between patients with chronic conditions and their clinicians: The case of diabetes. *Health Expectations, 9*(1), 25-36.
- Mulcahy, K., Maryniuk, M., Peeples, M., Peyrot, M., Tomky, D., Weaver, T., & Yarborough, P. (2003). Diabetes self-management education core outcomes measures. *The Diabetes Educator, 29*(5), 768-70, 773-84, 787-8 passim.
- Ngo-Metzger, Q., Telfair, J., Sorkin, D. H., Weidmer, B., Weech-Maldonado, R., Hurtado, M., & Hays, R. D. (2006). Cultural competency and quality of care: Obtaining the patient's perspective.
- Nicolucci, A., Burns, K. K., Holt, R., Comaschi, M., Hermanns, N., Ishii, H., . . . Stuckey, H. (2013). Research: Educational and psychological issues diabetes attitudes, wishes and needs second study (DAWN2TM): Cross-national benchmarking of diabetes-related psychosocial outcomes for people with diabetes. *Diabetic Medicine, 30*(7), 767-777.



North American Association for the Study of Obesity, National Heart, Blood Institute, National Institutes of Health (US), & NHLBI Obesity Education Initiative. (2000). *The practical guide: Identification, evaluation, and treatment of overweight and obesity in adults*. National Institutes of Health, National Heart, Lung, and Blood Institute, NHLBI Obesity Education Initiative, North American Association for the Study of Obesity.

Pallant, J. (2007). *SPSS survival manual: A step-by-step guide to data analysis using SPSS version 15*. Nova Iorque: McGraw Hill,

Patrick, H., & Williams, G. C. (2012). Self-determination theory: its application to health behavior and complementarity with motivational interviewing. *International Journal of behavioral nutrition and physical Activity*, 9(1), 18.

Peabody FW. The Care of the Patient. *JAMA*. 2015;313(18):1868.

Peyrot, M., Burns, K. K., Davies, M., Forbes, A., Hermanns, N., Holt, R., ... & Willaing, I. (2013). Diabetes Attitudes Wishes and Needs 2 (DAWN2): a multinational, multi-stakeholder study of psychosocial issues in diabetes and person-centred diabetes care. *Diabetes research and clinical practice*, 99(2), 174-184.

Peyrot, M., Rubin, R. R., Lauritzen, T., Skovlund, S. E., Snoek, F. J., Matthews, D. R., ... & Kleinebreil, L. (2005). International DAWN Advisory Panel. Resistance to insulin therapy among patients and providers: results of the cross-national Diabetes Attitudes, Wishes, and Needs (DAWN) study. *Diabetes Care*, 28(11), 2673-2679.

- Pilling, S. A., Williams, M. B., Brackett, R. H., Gourley, R., Weg, M., Christensen, A. J., . . . Reisinger, H. S. (2010). Part I, patient perspective: Activating patients to engage their providers in the use of evidence-based medicine: A qualitative evaluation of the VA project to implement diuretics (VAPID). *Implement Sci*, 5, 23.
- Popa-Lisseanu, M. G. G., Greisinger, A., Richardson, M., O'Malley, K. J., Janssen, N. M., Marcus, D. M., ... & Suarez-Almazor, M. E. (2005). Determinants of treatment adherence in ethnically diverse, economically disadvantaged patients with rheumatic disease. *The Journal of Rheumatology*, 32(5), 913-919.
- Powers, M. A., Bardsley, J., Cypress, M., Duker, P., Funnell, M. M., Fischl, A. H., . . . Vivian, E. (2015). Diabetes self-management education and support in type 2 diabetes: A joint position statement of the American diabetes association, the American association of diabetes educators, and the academy of nutrition and dietetics. *The Diabetes Educator*, 41(4), 417-430. doi:10.1177/0145721715588904 [doi]
- Rasch, G. (1960). Probabilistic models for some intelligence and achievement tests. Copenhagen: Danish Institute for Educational Research.
- Rask, K. J., Ziemer, D. C., Kohler, S. A., Hawley, J. N., Arinde, F. J., & Barnes, C. S. (2009). Patient activation is associated with healthy behaviors and ease in managing diabetes in an indigent population. *The Diabetes Educator*, 35(4), 622-630. doi:10.1177/0145721709335004 [doi]

- Rejeski, W. J., Ip, E. H., Bertoni, A. G., Bray, G. A., Evans, G., Gregg, E. W., & Zhang, Q. (2012). Lifestyle change and mobility in obese adults with type 2 diabetes. *New England Journal of Medicine*, *366*(13), 1209-1217.
- Remmers, C., Hibbard, J., Mosen, D. M., Wagenfield, M., Hoye, R. E., & Jones, C. (2009). Is patient activation associated with future health outcomes and healthcare utilization among patients with diabetes? *The Journal of Ambulatory Care Management*, *32*(4), 320-327.  
doi:10.1097/JAC.0b013e3181ba6e77 [doi]
- Reuben, D. B., & Tinetti, M. E. (2012). Goal-oriented patient care—an alternative health outcomes paradigm. *New England Journal of Medicine*, *366*(9), 777-779.
- Rickheim, P. L., Weaver, T. W., Flader, J. L., & Kendall, D. M. (2002). Assessment of group versus individual diabetes education: A randomized study. *Diabetes Care*, *25*(2), 269-274.
- Roberson, M. H. (1992). The meaning of compliance: Patient perspectives. *Qualitative Health Research*, *2*(1), 7-26.
- Robinson, J. H., Callister, L. C., Berry, J. A., & Dearing, K. A. (2008). Patient-centered care and adherence: Definitions and applications to improve outcomes. *Journal of the American Academy of Nurse Practitioners*, *20*(12), 600-607.
- Rubak, S., Sandbæk, A., Lauritzen, T., Borch-Johnsen, K., & Christensen, B. (2009). General practitioners trained in motivational interviewing can positively affect the attitude to

- behaviour change in people with type 2 diabetes: One year follow-up of an RCT, ADDITION denmark. *Scandinavian Journal of Primary Health Care*, 27(3), 172-179.
- Rubin, R. (Ed.). (2002). *Practical psychology for diabetes clinicians*. American Diabetes Association.
- Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, 55(1), 68.
- Ryan, R. M., Patrick, H., Deci, E. L., & Williams, G. C. (2008). Facilitating health behaviour change and its maintenance: Interventions based on self-determination theory. *European Health Psychologist*, 10(1), 2-5.
- Scholl, I., Koelewijn-van Loon, M., Sepucha, K., Elwyn, G., Légaré, F., Härter, M., & Dirmaier, J. (2011). Measurement of shared decision making—a review of instruments. *Zeitschrift Für Evidenz, Fortbildung Und Qualität Im Gesundheitswesen*, 105(4), 313-324.
- Shortus, T., Kemp, L., McKenzie, S., & Harris, M. (2013). 'Managing patient involvement': Provider perspectives on diabetes decision-making. *Health Expectations*, 16(2), 189-198.
- Skaer, T., Sclar, D., Markowski, D., & Won, J. (1993). Effect of value-added utilities on prescription refill compliance and medicaid health care expenditures—a study of patients with non-insulin-dependent diabetes mellitus. *Journal of Clinical Pharmacy and Therapeutics*, 18(4), 295-299.

- Steinsbekk, A., Rygg, L. Ø., Lisulo, M., Rise, M. B., & Fretheim, A. (2012). Group based diabetes self-management education compared to routine treatment for people with type 2 diabetes mellitus. A systematic review with meta-analysis. *BMC Health Services Research*, *12*(1), 1.
- Street, R. L., Jr, Gordon, H. S., Ward, M. M., Krupat, E., & Kravitz, R. L. (2005). Patient participation in medical consultations: Why some patients are more involved than others. *Medical Care*, *43*(10), 960-969. doi:00005650-200510000-00003 [pii]
- Stevens J (1996): Applied multivariate statistics for the social sciences, 3rd ed. Hillsdale, NJ, Lawrence Erlbaum
- Tabachnick, B. G., & Fidell, L. S. (1996). Using multivariate statistics. New York, NY: HarperCollins College Publishers.
- Tennstedt, S. L. (2000). Empowering older patients to communicate more effectively in the medical encounter. *Clinics in Geriatric Medicine*, *16*(1), 61-70.
- Tomky, D., Cypress, M., Dang, D., Maryniuk, M., Peyrot, M., & Mensing, C. (2008). AADE7™ self-care behaviors. *The Diabetes Educator*, *34*(3), 445-449.
- UK Prospective Diabetes Study (UKPDS) Group. (1998). Effect of intensive blood-glucose control with metformin on complications in overweight patients with type 2 diabetes (UKPDS 34). *The Lancet*, *352*(9131), 854-865.

- Vermeire, E., Hearnshaw, H., Van Royen, P., & Denekens, J. (2001). Patient adherence to treatment: Three decades of research. A comprehensive review. *Journal of Clinical Pharmacy and Therapeutics*, *26*(5), 331-342.
- Wagner, E. H., Bennett, S. M., Austin, B. T., Greene, S. M., Schaefer, J. K., & Vonkorff, M. (2005). Finding common ground: Patient-centeredness and evidence-based chronic illness care. *Journal of Alternative & Complementary Medicine*, *11*(supplement 1), s-7-s-15.
- Ward, B. W., Schiller, J. S., & Goodman, R. A. (2014). Multiple chronic conditions among US adults: A 2012 update. *Preventing Chronic Disease*, *11*, E62. doi:10.5888/pcd11.130389 [doi]
- Williams, G. C., Freedman, Z. R., & Deci, E. L. (1998). Supporting autonomy to motivate patients with diabetes for glucose control. *Diabetes Care*, *21*(10), 1644-1651.
- Williams, G. G., Gagné, M., Ryan, R. M., & Deci, E. L. (2002). Facilitating autonomous motivation for smoking cessation. *Health Psychology*, *21*(1), 40.
- Williams, G. C., Grow, V. M., Freedman, Z. R., Ryan, R. M., & Deci, E. L. (1996). Motivational predictors of weight loss and weight-loss maintenance. *Journal of Personality and Social Psychology*, *70*(1), 115.
- Williams, G. C., Lynch, M., & Glasgow, R. E. (2007). Computer-assisted intervention improves patient-centered diabetes care by increasing autonomy support. *Health Psychology*, *26*(6), 728.

- Williams, A., Manias, E., & Walker, R. (2008). Interventions to improve medication adherence in people with multiple chronic conditions: A systematic review. *Journal of Advanced Nursing*, *63*(2), 132-143.
- Williams, G. C., McGregor, H. A., King, D., Nelson, C. C., & Glasgow, R. E. (2005). Variation in perceived competence, glycemic control, and patient satisfaction: Relationship to autonomy support from physicians. *Patient Education and Counseling*, *57*(1), 39-45.
- Williams, G. C., McGregor, H. A., Zeldman, A., Freedman, Z. R., & Deci, E. L. (2004). Testing a self-determination theory process model for promoting glycemic control through diabetes self-management. *Health Psychology*, *23*(1), 58.
- Williams, G. C., Patrick, H., Niemiec, C. P., Williams, L. K., Divine, G., Lafata, J. E., . . . Pladevall, M. (2009). Reducing the health risks of diabetes: How self-determination theory may help improve medication adherence and quality of life. *The Diabetes Educator*, *35*(3), 484-492. doi:10.1177/0145721709333856
- Williams, G. C., Rodin, G. C., Ryan, R. M., Grolnick, W. S., & Deci, E. L. (1998). Autonomous regulation and long-term medication adherence in adult outpatients. *Health Psychology*, *17*(3), 269.
- Wong, C. K., Wong, W. C., Wan, E. Y., Wong, W. H., Chan, F. W., & Lam, C. L. (2015). Increased number of structured diabetes education attendance was not associated with the

improvement in patient-reported health-related quality of life: Results from patient empowerment program (PEP). *Health and Quality of Life Outcomes*, 13(1), 1.

Wright, B. D., & Stone, M. H. (1979). Best test design. Rasch measurement.

Ziemer, D. C., Berkowitz, K. J., Panayiotou, R. M., El-Kebbi, I. M., Musey, V. C., Anderson, L. A., . . . Phillips, L. S. (2003). A simple meal plan emphasizing healthy food choices is as effective as an exchange-based meal plan for urban African Americans with type 2 diabetes. *Diabetes Care*, 26(6), 1719-1724.



APPENDIX A

Seton Hall University  
Institutional (IRB) Approval



OFFICE OF INSTITUTIONAL  
REVIEW BOARD

## SETON HALL UNIVERSITY

June 29, 2016

Carol Mahler Hamersky  
34 Collins Drive  
Hillsborough, NJ 08844

Dear Ms. Hamersky,

The Seton Hall University Institutional Review Board has reviewed your research proposal entitled "Exploring the Relationship between Autonomy Support in Shared Decision Making and Patient Activation of Diabetes Self-Care Behaviors" and has categorized it as exempt.

Enclosed for your records is the signed Request for Approval form.

Please note that, where applicable, subjects must sign and must be given a copy of the Seton Hall University current stamped Letter of Solicitation or Consent Form before the subjects' participation. All data, as well as the investigator's copies of the signed Consent Forms, must be retained by the principal investigator for a period of at least three years following the termination of the project.

Should you wish to make changes to the IRB approved procedures, the following materials must be submitted for IRB review and be approved by the IRB prior to being instituted:

- Description of proposed revisions;
- *If applicable*, any new or revised materials, such as recruitment fliers, letters to subjects, or consent documents; and
- *If applicable*, updated letters of approval from cooperating institutions and IRBs.

At the present time, there is no need for further action on your part with the IRB.

*In harmony with federal regulations, none of the investigators or research staff involved in the study took part in the final decision.*

Sincerely,

Mary F. Ruzicka, Ph.D.  
Professor  
Director, Institutional Review Board

**REQUEST FOR APPROVAL OF RESEARCH, DEMONSTRATION OR RELATED ACTIVITIES INVOLVING HUMAN SUBJECTS**

All material must be typed.

**PROJECT TITLE: Exploring the relationship between autonomy support in shared decision making and patient activation of diabetes self-care behaviors**

**CERTIFICATION STATEMENT:**

In making this application, I(we) certify that I(we) have read and understand the University's policies and procedures governing research, development, and related activities involving human subjects. I (we) shall comply with the letter and spirit of those policies. I(we) further acknowledge my(our) obligation to (1) obtain written approval of significant deviations from the originally-approved protocol BEFORE making those deviations, and (2) report immediately all adverse effects of the study on the subjects to the Director of the Institutional Review Board, Seton Hall University, South Orange, NJ 07079.

*Carol Mahler Hamersky*

Carol Mahler Hamersky  
RESEARCHER(S)

May 29, 2016

DATE

\*\*Please print or type out names of all researchers below signature.  
Use separate sheet of paper, if necessary.\*\*

My signature indicates that I have reviewed the attached materials of my student advisee and consider them to meet IRB standards

*Genevieve Pinto Zipp PT, EdD*

6/1/16

RESEARCHER'S FACULTY ADVISOR (for student researchers only)  
DATE

Genevieve Pinto Zipp PT, EdD,  
Professor, Graduate Program in Health Sciences  
Seton Hall University  
School of Health and Medical Sciences

The request for approval submitted by the above researcher(s) was considered by the IRB for Research Involving Human Subjects Research at the June 2016 meeting.

The application was approved  not approved  by the Committee. Special conditions were  were not  set by the IRB. (Any special conditions are described on the reverse side.)

*Nancy J. Ruzicka, Ph.D.*  
DIRECTOR

6/29/16

DATE

SETON HALL UNIVERSITY INSTITUTIONAL  
REVIEW BOARD FOR HUMAN SUBJECTS RESEARCH

APPENDIX B

Geisinger Health System  
Institutional (IRB) Approval

## Geisinger Health System IRB Approval

Geisinger Institutional Review Board  
M.C. 30-69  
100 North Academy Avenue  
Danville, PA 17822  
570 271 8663 Tel  
570 214 7031 Fax

### Exemption Granted

May 27, 2016

Mary A Johnson  
GMC - Endocrinology

**IRB #: 2016-0232**, entitled *Exploring the relationship between autonomy support in shared decision making and patient activation of diabetes self-care behaviors*

RE: Submission Response for Initial Review Submission Form (only used with new study submission), 05/27/2016 02:01:03 PM EDT

Dear Mary A Johnson:

Your protocol was reviewed on 05/27/2016 and it was determined that your research protocol meets the criteria for **EXEMPTION** as defined in the U. S. Department of Health and Human Services Regulations for the Protection of Human Subjects [(45 CFR 46.101(b)]. You may now begin your research.

The specific exemption category under 45 CFR 46.101(b) is:

**Category 2: Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior unless, the information is obtained in an identifiable manner and any disclosure of the subjects responses outside of research could reasonably place the subject at risk.**

Submission Components			
Study Document			
Title	Version Number	Version Date	Outcome
GIRB protocol	Version 1.0	05/02/2016	Approved

Study Application	
Form Name	Outcome
Study Application	Approve

You are reminded that investigators whose research involving human subjects is determined to be exempt from the federal regulations for the protection of human subjects still have responsibilities for the ethical conduct of the research under state law and Geisinger IRB policy. Please be aware of the following policies and responsibilities for investigators:

Page 2 of 2

1. **Amendments** You are responsible for reporting any amendments to your research protocol that may affect the determination of the exemption and may result in your research no longer being eligible for the exemption that has been granted.
2. **Record Keeping** You are responsible for maintaining a copy all research related records in a secure location in the event future verification is necessary, at a minimum these documents include: the research protocol, the claim of exemption application, all questionnaires, survey instruments, interview questions and/or data collection instruments associated with this research protocol, recruiting or advertising materials, any consent forms or information sheets given to subjects, or any other pertinent documents.

Please use your research protocol number (listed above) on any documents or correspondence with the IRB concerning your research protocol.

If you have any questions or need further help, please contact the Human Research Protection Program staff at 570-271-8663.

Sincerely,  
Thomas D Challman, MD  
IRB Chair  
Institutional Review Board

CC: Carol M Hamersky

GHS System generated message

**Geisinger Health System IRB Approval, May 27, 2016**

**Regarding:** 2016-0232 - "Exploring the relationship between autonomy support in shared decision making and patient activation of diabetes self-care behaviors"  
**Submission Type:** Submission Response for Initial Review Submission Form (only used with new study submission)

**Principal Investigator:** Mary A Johnson, **Co-Principal Investigator:** Carol Hamersky  
**Reference Number:** 015000

**Please do not respond to this message. These messages are automatically generated from the IRIS system.**

Please log into IRIS at <https://irb.geisinger.edu>

Attached is the outcome letter for this submission.  
Thank You

**Geisinger Institutional Review Board**  
M.C. 30-69  
100 North Academy  
Avenue Danville, PA  
17822  
570 271 8663 Tel  
570 214 7031 Fax  
Page | 1

**Re: Hamersky PI****From:** Sober, Rosa [mailto:[rmsober@geisinger.edu](mailto:rmsober@geisinger.edu)]**Sent:** Wednesday, June 01, 2016 3:50 PM**To:** CAHY (Carol Hamersky)**Cc:** Johnson, Mary A.**Subject:** Exploring the relationship between autonomy support in shared decision making and patient activation of diabetes self-care behaviors

Dear Carol,

As part of Geisinger Health System IRB requirements, a GHS employee must be listed as the Primary Investigator on the IRB application in our system. That is for internal purposes only and so we have a responsible person in our institution. You can be the lead investigator on the project for outside of Geisinger items, such as publishing. You are currently listed as the Co-Investigator/Sub-Investigator to complete this study and are listed as study contact for all correspondences.

Geisinger Health System IRB Approval-May 27, 2016

Sincerely,

**Rosa Sober CIP**

Manager, HRPP

Geisinger Health System IRB Office

100 North Academy Ave

Danville, PA 17822

Office Phone: (570) 214-6725

Fax: (570) 214-7031

[rmsober@geisinger.edu](mailto:rmsober@geisinger.edu)

---

**IMPORTANT WARNING:** The information in this message (and the documents attached to it, if any) is confidential and may be legally privileged. It is intended solely for the addressee. Access to this message by anyone else is unauthorized. If you are not the intended recipient, any disclosure, copying, distribution or any action taken, or omitted to be taken, in reliance on it is prohibited and may be unlawful. If you have received this message in error, please delete all electronic copies of this message (and the documents attached to it, if any), destroy any hard copies you may have created and notify me immediately by replying to this email. Thank you. Geisinger Health System utilizes an encryption process to safeguard Protected Health Information and other confidential data contained in external e-mail messages. If email is encrypted, the recipient will receive an e-mail instructing them to sign on to the Geisinger Health System Secure E-mail Message Center to retrieve the encrypted e-mail.

APPENDIX C

Letter of Solicitation to Survey Participants



## Letter of Solicitation for Participation

You are receiving this email as a patient at Geisinger Health System who has been diagnosed with diabetes.

I am a Doctoral student at Seton Hall University, who is conducting a study that seeks to explore autonomy support in shared decision making on patient activation of diabetes self-care behaviors. This is about understanding what is important to you when you meet with your clinician on taking care of your diabetes.

I am looking for volunteers already diagnosed with diabetes to take part in this study. Participation is voluntary and all answers provided are anonymous.

If you are willing to take part in this study, click on the link at the end of this email to open a confidential on-line survey. There are 5 demographic questions at the beginning of the survey. After that you will be asked to complete the Health Care Climate Questionnaire (HCCQ) and Patient Activation measure (PAM 13<sup>tm</sup>). It should take you less than 15 minutes to complete this survey. I hope that the information obtained from this research study will provide health care clinicians with valuable insight to assist their patients with Diabetes self-care behaviors and ultimately health outcomes.

By completing this survey, you give consent to participating in this research study. Participation is completely on a voluntary basis. There is no penalty for not participating. This study is entirely confidential and there are no known risks to completing this survey. All de-identified data will be password protected and stored on a USB memory key and kept in a locked/secured cabinet which only the study advisor and principal investigator will have access to.

*By clicking on the link below and accessing survey, you are indicating that you have read and understood this information presented above and agree to participate in this research study.*

<https://www.surveymonkey.com/>

APPENDIX D

Patient Survey

## Exploring Autonomy support and patient activation level survey

### 1. General Demographic Questions

As we seek to understand more about health care management teams and Diabetes care, we greatly appreciate your completion of the following survey which contains 3 sections. Section one contains general demographic questions, section two contains the Health-Care Climate Questionnaire and section three contains the Patient Activation Questionnaire. Completion of this survey is anonymous and voluntarily and thus your submission of the completed survey acknowledges your consent to participate in the study.

1. What is your age in (years)?

- a. 18-30
- b. 31-40
- c. 41-50
- d. 51-60
- e. 61-70
- f. 70 +

2. What is your gender?

- a. Female
- b. Male
- c. Would not prefer to identify

3. How many years have you had diabetes (fill in number in years)?

4. Please note the number of previous diabetes education session(s) you have experienced (including both individual session(s) and group session(s) you have engaged in).

- a. None
- b. 1-3
- c. 4-6
- d. ≥ 6

5. What is the highest degree you have been awarded?

- a. Less than high school
- b. High school graduate
- c. Associate college degree
- d. Bachelor's degree
- e. Graduate degree
- f. Doctorate degree
- g. Other

6. What is your current household income?

- a. Less than \$20,000
- b. \$20,000 to \$34,999
- c. \$35,000 to \$49,999
- d. \$50,000 to \$74,999
- e. \$75,000 to \$99,999
- f. \$100,000 to \$149,999
- g. \$150,000 or more

## Exploring Autonomy support and patient activation level survey

### 2. Health-Care Climate Questionnaire

**This questionnaire contains items related to your visits with your health care providers (such as the conversation and relationship). Health-care providers have different styles in dealing with patients, and we would like to know more about how you feel about your prior encounters with your health care providers. Your responses are confidential. Please be honest and candid. Your responses to the questions can be ranked from 1 (strongly disagree) to 7 (Strongly Agree).**

**In general,**

7. I feel that my team of health care providers have offered me choices and options.

Strongly Disagree				Neutral				Strongly Agree
1	2	3	4	5	6	7		
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		



15. My team of health care providers answers my questions fully and carefully.

Strongly Disagree				Neutral			Strongly Agree
1	2	3	4	5	6	7	
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. My team of health care providers listens to my perspective on how I would like to manage my condition.

Strongly Disagree				Neutral			Strongly Agree
1	2	3	4	5	6	7	
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17. My team of health care providers is aware of patient's emotions and addresses them appropriately

Strongly Disagree				Neutral			Strongly Agree
1	2	3	4	5	6	7	
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

18. I feel that my team of health care providers cares about me as a person.

Strongly Disagree				Neutral			Strongly Agree
1	2	3	4	5	6	7	
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

19. I don't feel good about the way my team of health care providers talk to me.

Strongly Disagree				Neutral			Strongly Agree
1	2	3	4	5	6	7	
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

20. My team of health care providers tries to understand how I see things before suggesting a new way to approach my condition.

Strongly Disagree				Neutral			Strongly Agree
1	2	3	4	5	6	7	
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

21. I feel able to share my feelings with my team of health care providers.

Strongly Disagree				Neutral			Strongly Agree
1	2	3	4	5	6	7	
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### Exploring Autonomy support and patient activation level survey

#### 3. Health-Care Climate Questionnaire: visits

In order to help understand the importance of health care visits for individuals living with diabetes, please complete the following 2 questions below.

22. How would you describe your visits for Diabetes management with your team of health care providers?

23. What is the most important factor to you in your visits for diabetes management with your team of health care providers?

### Exploring Autonomy support and patient activation level survey

#### 4. Patient Activation Questionnaire

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by selecting the appropriate answer. Your answers should be what is true for you and not just what you think others want you to say.

Your choices are Disagree Strongly (1), Disagree (2), Agree (3) or Agree Strongly (4). If the statement does not apply to you, mark N/A.

24. When all is said and done, I am the person who is responsible for taking care of my health.

Disagree Strongly (1)	Disagree (2)	Agree (3)	Agree Strongly (4)	N/A (Not Applicable)
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. Taking an active role in my own health care is the most important thing that affects my health.

Disagree Strongly (1)	Disagree (2)	Agree (3)	Agree Strongly (4)	N/A (Not Applicable)
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

26. I am confident I can help prevent or reduce problems associated with my health.

Disagree Strongly (1)	Disagree (2)	Agree (3)	Agree Strongly (4)	N/A (Not Applicable)
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

27. I know what each of my prescribed medications do.

Disagree Strongly (1)	Disagree (2)	Agree (3)	Agree Strongly (4)	N/A (Not Applicable)
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

28. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.

Disagree Strongly (1)      Disagree (2)      Agree (3)      Agree Strongly (4)      N/A (Not Applicable)

29. I am confident that I can tell a doctor concerns I have even when he or she does not ask.

Disagree Strongly (1)      Disagree (2)      Agree (3)      Agree Strongly (4)      N/A (Not Applicable)

30. I am confident that I can follow through on medical treatments I may need to do at home.

Disagree Strongly (1)      Disagree (2)      Agree (3)      Agree Strongly (4)      N/A (Not Applicable)

31. I understand my health problems and what causes them.

Disagree Strongly (1)      Disagree (2)      Agree (3)      Agree Strongly (4)      N/A (Not Applicable)

32. I know what treatments are available for my health problems.

Disagree Strongly (1)      Disagree (2)      Agree (3)      Agree Strongly (4)      N/A (Not Applicable)

33. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising.

Disagree Strongly (1)      Disagree (2)      Agree (3)      Agree Strongly (4)      N/A (Not Applicable)

34. I know how to prevent problems with my health.

Disagree Strongly (1)      Disagree (2)      Agree (3)      Strongly Agree (4)      N/A (Not Applicable)

35. I am confident I can figure out solutions when new problems arise with my health.

Strongly Disagree (1)      Disagree (2)      Agree (3)      Strongly Agree (4)      N/A (Not Applicable)

36. I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress.

Strongly Disagree (1)      Disagree (2)      Agree (3)      Strongly Agree (4)      N/A (Not applicable)



37. Please indicate your usual medical clinic below:

Endocrinology clinic

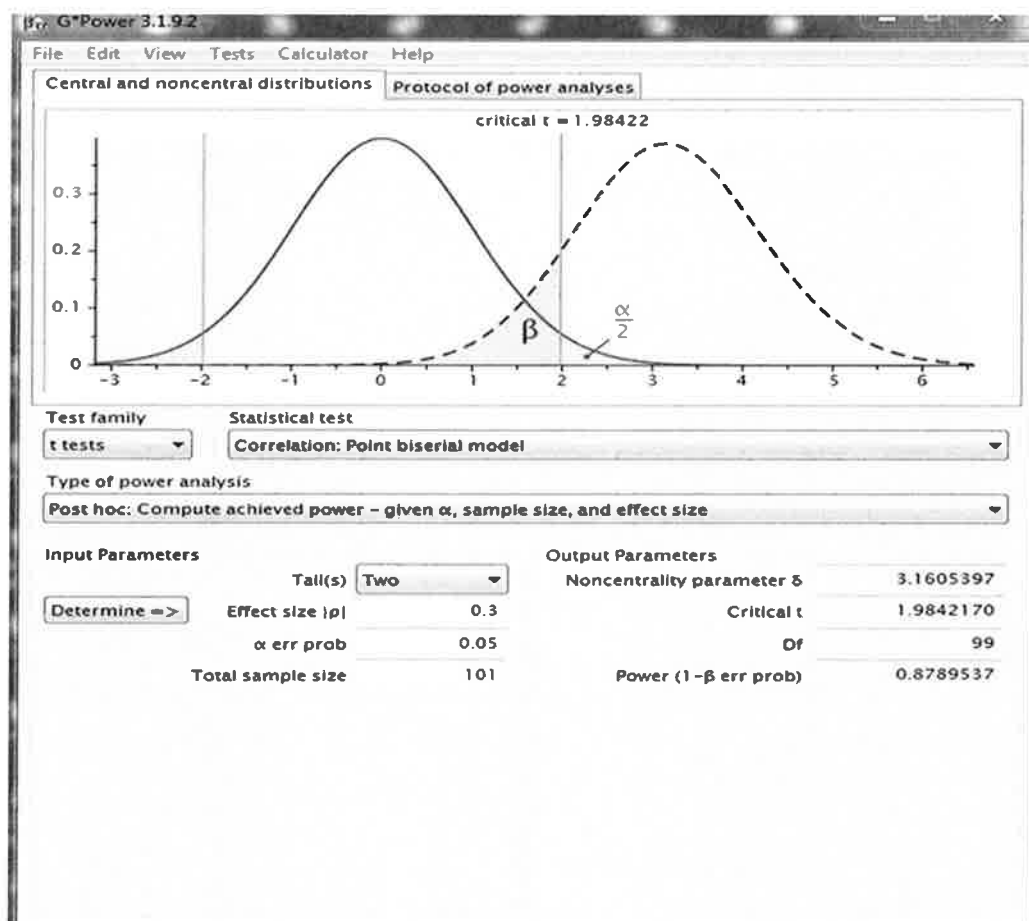
Other Medical clinic

Thank you for participating in this research survey. Your time and consideration is greatly appreciated.

APPENDIX D

G\*Power Post hoc Analyses

## Post Hoc G\*Power Analysis Correlation



## Post Hoc G\*Power Analysis- Multiple Regression

