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Development of a Collaborative Goal Setting Measure for Patients with Diabetes

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Development of a Collaborative Goal Setting Measure for Patients with Diabetes

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

by

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DEVELOPMENT OF A COLLABORATIVE GOAL SETTING MEASURE FOR PATIENTS WITH DIABETES

By Heather Lynne Morris, Ph.D.

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

Virginia Commonwealth University, 2014.

Major Director: Jennifer Elston Lafata, Professor Social and Behavioral Health

Introduction: The potential benefits of collaborative goal setting in the clinical setting have been shown. However, we have a limited understanding about what needs to have transpired between a patient and his or her clinician for them to report that they engaged in collaborative goal setting. Therefore, our ability to monitor and foster collaborative goal setting remains limited.

Methods: My three-manuscript dissertation used a mixed-methods approach utilizing both qualitative and quantitative research methods. The aims of my study were to: (1) develop a conceptual model of collaborative goal setting as perceived by patients; (2) generate a list of survey items for possible inclusion in a measure of collaborative goal setting, using results from patient focus groups and input from an expert panel; and (3) administer the collaborative goal setting measure to a sociodemographically diverse sample of patients with diabetes and test the psychometric properties of the measure.

Results: Study 1 found that patients described collaborative goal setting as containing four distinct domains that occurred within the context of a caring relationship with their health care provider: (1) listen and learn from each other; (2) share ideas honestly; (3) agree on a measurable

objective; and (4) support for goal achievement. Patients also articulated clear responsibilities for themselves and their clinicians within each domain and described collaborative goal setting as a process that occurs over time.

Study 2 found that the second-order factor analysis supported the proposed measurement structure of a 37-item measure of patient-perceived collaborative goal setting. Overall model fit of the first-order model was good ($\chi = 4366.13$, $p<.001$; RMSEA = .08). The internal consistency of the second-order model scales [caring relationship, listen and learn, share ideas, agree on a measurable objective, and support for goal achievement] were very high ($\alpha = .89$-$.94$) as was the reliability (Mcdonald's $\Omega = .819$).

Study 3 found that the only significant pathway was the relationship between collaborative goal setting and self-management, which was partially mediated by self-efficacy ($p<.05$). After controlling for a variety of socio-demographic characteristics, the partial mediation model with self-efficacy was no longer significant ($p=.055$), however, the direct effects remained significant: self-management and collaborative goal setting ($p<.001$) and self-efficacy ($p<.001$), as well as self-efficacy on collaborative goal setting ($p<.05$).

Discussion: Findings from these three studies support the new measure of collaborative goal setting developed from patient perceptions of this process.

Chapter 1: Introduction

The prevalence of diabetes in the United States is growing at a staggering rate. Approximately 25.8 million Americans, or 8.3% of the U.S. population have diabetes[1] and it affects all socioeconomic classes, both genders, as well as all races.[2] Despite the availability of effective pharmacological and other treatments, recommended target levels of hemoglobin (Hb) A1c, blood pressure, and cholesterol are often not achieved among patients with diabetes.[3-5] When patients with diabetes fail to appropriately manage their cardio-metabolic risk factors, it leads to higher rates of morbidity and mortality[6-8] as well as substantial economic burdens placed upon both patients and the health care system.[9]

The act of managing an illness like diabetes involves a number of self-management behaviors that the patient is responsible for executing on a regular basis including diet, exercise and a complicated medication regimen.[10] While physicians recommend medications, tests, and procedures, patients are the ones who must oversee implementation across extended periods of time. In 1990, Wagner and colleagues proposed the Chronic Care Model as a means to identify the components of a health care system that are needed for the provision of high-quality disease management.[11] This model illustrates the importance of productive interactions between informed, activated patients and their prepared, proactive practice team to the achievement of improved health outcomes. One key component of these productive interactions is collaborative goal setting.[12]

The American Diabetes Association (ADA) has recognized collaborative goal setting as a critical component of high quality diabetes care.[13] Conceptually, goal setting is considered to be a collaborative process when the patient is an active participant in creating his or her own care.[14] According to Heisler et al. (2003), in a collaborative interaction, the patient and the

physician (1) share responsibility for making decisions, (2) mutually agree upon the goal, (3) discuss self-care management options, and the patient shares (4) beliefs about illness treatment and (5) information about their life and values.[15]

Recent findings from our team[16] and those from others[17] have empirically highlighted the potential benefits of collaborative goal setting in the clinical setting. In both of these previous studies, when patients reported engaging in collaborative goal setting with their clinicians, the probability that their cardio-metabolic risk factors were appropriately controlled increased.[17, 18] These studies highlight the importance of collaborative goal setting as *perceived* by patients. In practice, however, we know little about what needs to have transpired between a patient and his or her clinician for them to report that they engaged in collaborative goal setting. As such, our ability to monitor and foster collaborative goal setting as perceived by patients remains limited.

Current challenges in measuring collaborative goal setting

While direct observation of patient-physician interactions is one means by which to assess the occurrence of collaborative goal setting, relying on this method would be cost prohibitive and unfeasible in practice. Furthermore, there is growing evidence that patient perceptions of communication exchanges may not be consistent with those documented by non-participating observers.[19-21] Such findings therefore challenge the appropriateness of relying on observational and other measures that do not consider patient perceptions. On the other hand, the use of patient-reported measures for quality monitoring can be done efficiently and is consistent with practices already in use.[22-24]

To date, our understanding of the patient's perception of collaborative goal setting primarily stems from research that has relied on a subset of items contained within the Patient Assessment of Chronic Illness Care [PACIC].[25, 26] The PACIC, although designed to measure

the concordance of care delivery with the Chronic Care Model from the patients' perspective, was not designed to measure collaborative goal-setting processes specifically. The measure does however include one subcomponent (goal setting/tailoring) that, among other things, examines goal setting processes in practice. The three items specific to goal setting (i.e. (1) asked to talk about my goals in caring for my diabetes; (2) helped to set specific goals to improve my eating or exercise; and (3) set a goal together with my team for what I could do to manage my diabetes) asks respondents to rate how often each occurred over the past six months using a Likert scale that ranges from 1 (Never) to 5 (Very Often). Overall PACIC scores have been repeatedly associated with care quality,[12, 25-28] and as indicated above, at least two studies have specifically used this instrument to evaluate the associations between patient perceptions of engaging in collaborative goal setting and improved outcomes. In both these studies, patient reports of engaging in collaborative goal setting with their physician were found to be indirectly associated with improved clinical control among patients with diabetes.[16, 17]

The ongoing challenge with using the PACIC within such evaluations is that each of the PACIC items leaves the definition of collaborative goal setting up to the respondent. As such, these items do not offer insight into how patients perceive a goal setting process as collaborative or how a collaborative goal setting process might be fostered in practice. So, while the benefits of collaborative goal setting are rarely debated, our understanding of how to monitor and foster this process in the clinical setting is limited by our lack of knowledge regarding what needs to transpire for a patient to label a goal setting process as collaborative as well as our inability to monitor for and measure the occurrence of that process in practice.

Collaborative goal setting and its impact on health

According to the ADA, the act of setting goals around behavior change is a key component of diabetes self-management programs.[13] Research specific to fostering goal setting in the care of patients with diabetes has found that patients are capable of selecting goals that are appropriate to their clinical situation, and have a higher likelihood of success when they take a role in setting a goal.[29, 30] However, the act of creating a goal does not spontaneously instill the motivation necessary for attainment, and may not be effective if it conflicts with other aspirations of the individual.[31] When an individual has an interest in achieving an objective, goal setting can motivate a higher quality of performance than if no goals were present.[31]

Among patients with diabetes, patient perceptions' of collaborative care (including collaborative goal setting) have been shown to be associated with patients' reported self-management,[32] and helping patients set and follow up on goals collaboratively may be an effective way to help patients improve their self-efficacy. Self-efficacy is an important predecessor to effective self-management, and thus glycemic control and other patient-centered outcomes.[33] The act of collaboratively setting goals may be beneficial to the patient-clinician relationship, which can improve factors such as patient trust, which has been shown to improve patient adherence to recommended treatment.[34] In addition, improved patient-physician collaboration has led to improved outcomes by promoting greater agreement on treatment goals and strategies indicating that patients and clinicians with a similar view on treatment goals may work better together,[35-39] and patients who shared responsibility with their physician regarding treatment decisions more often agreed with their physician regarding treatment strategies.[15] Findings from Heisler et al. (2003) support the idea that a higher level of concordance between patients and their physicians on goals and strategies may be a method by which better patient-provider communication and collaboration can contribute to improved patient outcomes.[15]

The impact of patient trust, knowledge, self-efficacy, and self-management

The method by which physicians communicate with patients and provide information has the potential to improve a patient's self-management.[32] Communication can foster a sense of trust between a patient and their clinician(s), an essential component in chronic illness management that may influence patient health outcomes in a number of ways. Trust has been defined as an individual viewing the other party as competent, ethical, responsible and caring.[40] Good communication from a physician provides patients with an appropriate amount of understanding and the tools necessary to maintain self-management while also enhancing the patient's level of trust.[41] A patient's trust in the physician has the potential to reduce his or her uncertainty and increase their sense of control. This thereby contributes to a patient's cognitive appraisals of self-efficacy in regards to their chronic illness, adherence to recommended treatment,[34] self-management choices,[42-44] and ultimately with glycemic control.[45-47]

A patient's knowledge regarding their condition is another hypothesized influence on overall self-management of diabetes. Previous studies have indicated that an increase in knowledge leads to an increase in the patient's self-efficacy,[48-52] and patient's that had an increased understanding of their condition had better self-management behaviors[32, 53] and increased levels of self-efficacy.[54, 55] While knowledge influences self-management, it also plays an important role in the development of self-efficacy. However, 50% of patients leave the doctor's office with little understanding of what the doctor had recommended.[41]

The amount of self-efficacy a person has in making their own healthcare decisions, and the trust they have in the healthcare team can affect their self-management choices.[43] For example, previous studies indicate that self-efficacy impacts adherence to treatment and therefore has an impact on clinical outcomes.[56] Self-efficacy is predictive of an individual's

future behavior and can either promote or prohibit appropriate actions,[57-59] and has been shown to be important in the self-management of diabetes.[60, 61] As previously indicated, self-management is a vital role for people with type 2 diabetes, and is often left to the responsibility of the patient with little to no support. Recent studies have shown that people who have defined health goals have more effective self-care behaviors,[62-65] and interventions aimed at improving self-management behaviors have resulted in improvements in glycemic control.[10, 32, 33, 66]

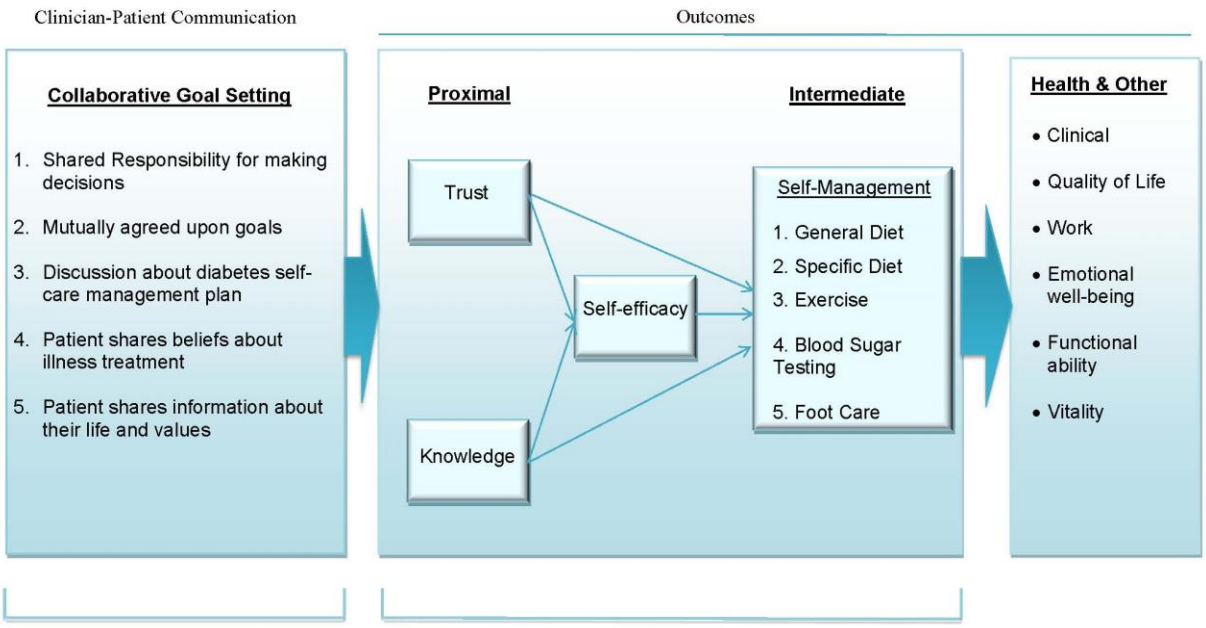
Conceptual Framework

The conceptual framework for the proposed research is adapted from the Conceptual Model of Patient-Provider Concordance proposed by Heisler et al. (2003) and the Pathways from Communication to Health Outcomes model proposed by Epstein & Street (2007) (Figure 1.1).[15, 67] Using the framework proposed by Heisler and colleagues, I propose that collaborative goal setting is composed of: (1) shared responsibility for making decisions (2) a mutually agreed upon goal (3) discussion about diabetes self-care management plan (4) patients sharing beliefs about illness treatment, and (5) patients sharing information about their life and values. The Conceptual Model of Patient-Provider Concordance suggests that the degree of concordance between the patient and clinician in regards to treatment goals and strategies impacts the patient's health outcomes.[15]

The pathways from Communication to Health Outcomes model posits that (1) the interaction between the patient and clinician is interconnected and therefore both participants should be actively involved to promote improved health outcomes and (2) there are a number of paths through which patient-clinician communication lead to improved health outcomes. In the context of the proposed research, I will focus on the critical pathways that have been discussed by previous researchers in the goal-setting field. As such, the conceptual framework proposed

here informs the overall pathway from the patient and clinician goal setting process to important patient self-management perceptions and skills to associated health outcomes. As self-management has been previously linked to health outcomes, my focus will be the relationship between collaborative goal setting and the proximal and intermediate outcomes hypothesized to mediate the relationship between collaborative goal setting and self-management.

Figure 1.1 Conceptual Framework of Collaborative Goal Setting



Adapted from Heisler's (2003) Framework of Patient & Provider Factors Influencing Effects of Concordance

Adapted from Street & Epstein's Pathways from Communication to Health Outcomes Model

Aims of my research

The overarching goal of my dissertation research is to understand the meaning of collaborative goal setting from the patient's perspective and to develop a patient-reported measure for assessing and fostering the use of collaborative goal setting between adult primary care patients with diabetes and their clinicians. As such, findings will be able to be used to foster

collaboratively set goals in the clinical setting as well as to advance our understanding of how to monitor for and measure the impact of collaborative goal setting in practice. Specifically, I will:

Aim 1: Develop a conceptual model of collaborative goal setting as perceived by patients.

Aim 2: Generate a list of survey items for possible inclusion in a measure of collaborative goal setting, using results from patient focus groups and input from an expert panel.

Aim 3: Administer the collaborative goal setting measure to a sociodemographically diverse sample of patients with diabetes and test the psychometric properties of the measure. The latter will include testing the following hypotheses:

H_1: Consistent with the multi-dimensional framework of collaborative goal setting proposed by Heisler and Smith et al. (2003),[15] confirmatory factor analysis will identify five domains of collaborative goal setting (i.e. shared responsibility for making decisions, a mutually agreed upon goal, discussion about diabetes self-care management plan, patient shares beliefs about illness treatment, and patient shares information about their life and values).

H_2: Reliability of the model, as estimated from omega and alpha coefficients, will be high (>0.80).[68]

H_3: Collaborative goal setting scores will be positively associated with trust in their clinician, knowledge of their illness, and self-efficacy among patients with diabetes.

H_4: Collaborative goal setting scores will be positively associated with self-management skills among patients with diabetes.

Chapter 2/Paper 1: Adding the patient's voice to our understanding of collaborative goal setting: How do patients with diabetes perceive collaborative goal setting?

Abstract

Purpose: Collaborative goal setting, when perceived by patients as having occurred, has been shown to be associated with improved patient health outcomes. Yet, our knowledge of how to foster this process in practice is hindered by our limited understanding of what needs to transpire for patients to denote a goal setting process as 'collaborative'. The purpose of this study is to use qualitative research methods to explore how patients perceive collaborative goal setting and what they report must have happened for a goal to be labeled as 'collaborative.'

Methods: Four focus groups, stratified by diabetes control, were conducted among 19 patients with diabetes. A semi-structured focus group guide was used to explore patient perceptions of collaborative goal setting and patient reports of what needed to happen for goals to be considered collaboratively set. Focus group transcripts were coded using thematic analysis. Focus group recruitment continued until theoretical saturation was reached.

Results: Patients described collaborative goal setting as containing four distinct domains that occurred within the context of a caring relationship with their health care provider: (1) listen and learn from each other; (2) share ideas honestly; (3) agree on a measurable objective; and (4) support for goal achievement. Patients also articulated clear responsibilities for themselves and their clinicians within each domain and described collaborative goal setting as a process that occurs over time.

Conclusions: Patients perceived collaborative goal setting as a multi-dimensional process that occurs over time within the context of a caring relationship and one that encompasses distinct patient and clinician responsibilities.

Introduction

The benefits of collaborative goal setting are generally well recognized. [69, 70] Among patients with diabetes, research demonstrates that patient perceptions of collaborative care, including collaborative goal setting, are associated with better patient-reported self-management behaviors and glycemic control.[16, 32] The American Diabetes Association (ADA) recognizes collaborative goal setting between patients and their clinicians as a critical component of high quality diabetes care.[13]

Despite known benefits and recommendations, our understanding of what constitutes collaborative goal setting in health care is remarkably limited. Measurement instruments such as the Patient Assessment of Chronic Illness Care [PACIC], [25] while enabling an understanding of the benefits of collaborative goal setting, leave the definition of collaborative goal setting up to the respondent. In doing so, such patient-reported tools offer little insight into what communicative or other transactions transpired between a patient and clinician for the patient to report that collaborative goal setting occurred. As such, the patient's voice remains effectively silent in current efforts to foster collaborative goal setting in practice.

Because prior research has illustrated differences in what observers and patients consider as, for example, shared decision making,[19-21] there is reason to believe that differences between patients' and others' perceptions may also exist in what constitutes a goal that is collaboratively set. It is therefore important to understand how patients perceive collaborative goal setting if we want to be able to foster of goal-setting processes that are likely to lead to beneficial outcomes. The purpose of this study is to use qualitative research methods to explore how patients perceive collaborative goal setting and what they report must happen for goal setting processes to be labeled as 'collaborative.'

Methods

Study Setting and Participant Recruitment

Study eligible patients were those currently diagnosed with diabetes and receiving primary care within the Virginia Commonwealth University Health System (VCU-HS), the largest safety net provider in central Virginia. In April 2013, the VCU-HS electronic health record (EHR) system was queried to identify individuals aged 40 years or older who had at least two outpatient visits to a primary care clinic with an associated diagnostic code for diabetes (i.e., ICD-9 =250.X) in the prior 6 months. The eligible population was further limited to those with a hemoglobin (Hb) A1c test in March or April 2013, and an outpatient visit in the previous month. The latter was done to enable a recent office-based discussion from which the participant could draw experiences. From among these study eligible patients, random sampling was used to identify a sample of n=200 potential study participants.

Each of these 200 patients was mailed a letter of study introduction in February 2013. The study principal investigator (HLM) placed follow-up telephone calls to determine interest and confirm eligibility. Since the study protocol specified a minimum of four focus groups, (with additional groups to be conducted if saturation was not achieved) eligible individuals initially were recruited to one of four focus groups until all groups were filled (i.e., n=12 per group recruited). Twelve participants per focus group were recruited with a goal of eight attending each focus group.[71, 72] In case there were differences in experiences of goal setting, recruitment was stratified by HbA1c control: two groups for individuals with an HbA1c <8%, and two groups with an HbA1c $\geq$ 8%. Focus group participants received a $25 gift card to one of two local retail stores of their choosing.

Data Collection

Focus groups were chosen for data collection for two primary reasons. First, the use of focus groups enabled an organized conversation about collaborative goal setting with small groups of patients that represented segments of the general patient population with diabetes (in this case, individuals whose disease was and wasn't optimally controlled).[73] Second, the focus group process capitalized on group dynamics, and thereby enabled a shared understanding of patient views on collaborative goal setting.[74, 75]

All focus groups were conducted at a community-based hypertension clinic and were moderated by the study PI using a semi-structured moderator guide. (Appendix A) Questions for the moderator guide were developed using the conceptualization of collaborative goal setting proposed by Heisler et al (2003).[15] In that study, Heisler (2003) hypothesized that collaborative goal setting consists of five key domains: patients and clinicians (1) sharing responsibility for making decisions, (2) mutually agreeing upon the goal, (3) discussing self-care management options, and the patient sharing (4) beliefs about illness treatment and (5) information about their life and values.[15] Using this conceptualization as a reference, the guide was divided into topical areas, each of which contained a series of open-ended questions regarding patient health-related goals and goal setting processes. (Table 2.1) Written consent was obtained from all participants prior to participation and all focus group sessions were audio-recorded and attended by a facilitator. The VCU Institutional Right Board (IRB) approved all aspects of the study protocol.

Data analysis

Each of the focus group audio-recordings was transcribed prior to analysis. Two authors (HLM and JEL) reviewed the transcripts independently and coded for thematic content across all focus groups. Each author assessed the transcripts for patterns or themes that emerged within the

data relevant to collaborative goal setting. After evaluating the fourth focus group, the data appeared to be robust and no new information emerged in regards to collaborative goal setting. Based upon the lack of additional concepts, theoretical saturation was considered and no additional focus groups were conducted. Furthermore, as no substantive differences in themes were identified by glycemic control, results were pooled across all four focus groups.

Emergent themes were organized into conceptual domains of collaborative goal setting and then presented to an expert panel that consisted of a primary care physician, a communication specialist, and a health psychologist. The expert panel was utilized to discuss the development of each of the domains. Members of the expert panel were presented findings from the focus group as well as the proposed group of themes. Each member provided feedback regarding domain placement and the final domains were confirmed by the panel. Atlas.ti 6.2 was used to assist with data management and analysis.

Results

Sample Characteristics

Of the 168 individuals who were contacted to participate, five were unable to participate due to health or transportation concerns, one was unable to participate because they did not speak English, 30 were unable to be reached (did not have a working phone number or did not answer), and 84 declined to participate, resulting in 48 individuals who agreed to participate. Among those who agreed to participate, a total of 19 individuals attended a focus group (ten among the two groups for individuals in glycemic control and nine among the two groups for individuals not in glycemic control). Table 2.2 shows the demographic characteristics of the individuals contacted and those who attended a focus group. Similar to the underlying patient population, focus group participants were predominately female (68%) and African American (79%).

Themes Identified

Overall, participants described that it was important for collaborative goal setting to occur within the context of a caring relationship. Focus group participants repeatedly discussed how collaborative goal setting started with an existing relationship with the clinician. For example, a participant in one focus group said in response to what would make them more likely to engage in collaborative goal setting:

> *"I think sometimes the doctor would understand you a lot better if they understood some of your situations. Why your blood sugar is so high, or… our eating habits, our lifestyles. [But] you have to work together. [the doctor has to have] a little more compassion, take a little more time to get to know [their] patients." [Focus Group 3, Participant 1]*

Within this context, a caring relationship could be demonstrated in a number of ways. Clinicians with "a good bedside manner," were thought to be caring as were those who were compassionate, and sensitive to patient needs. Patients expressed a number of times the importance of a relationship with the clinician where the clinician was concerned and cared about them, and not just mechanistically treating their illness. When asked why they like to be involved in a collaborative discussion, one patient said:

> *"[My doctor], now he is very concerned. He will fuss at you and he will do whatever is necessary for you…I wouldn't trade [him] in for nothing in the world." [Focus Group 2, Participant 3]*

Patients also expressed that the clinician could show they cared by taking the time to speak with them. Not only did patients state that they wanted clinicians to take their time when speaking to them, but that clinicians were also responsible for giving them enough time to discuss what was on their mind and not rush them. When patients felt rushed, they were left feeling as if they did not have enough time to discuss all matters. When asked what makes a goal collaborative, one participant said:

"[There] might not always be time to talk about it. But it's important to share if you think there is something important about what the doctor said." [Focus Group 3, Participant 3]

In order to take time to care, participants expressed that it was the responsibility of both the patient and the clinician to be honest with each other. Clinicians were described as responsible for telling patients exactly what the situation is, including potential risks, without holding back. The same was said for patients. They have a responsibility to answer questions in a truthful manner in order for them to truly benefit from the care they received. In response to being asked what's important to do or say when setting a collaborative goal, one participant responded:

"You, both of you, you and the physician have to be totally honest with each other…If you are not honest, you [are] going to suffer."[Focus Group 4, Participant 1]

Within the context of this caring relationship, the second theme that emerged was the need for both patients and physicians to listen and learn from one another. Patients emphasized that setting a collaborative goal was not one-sided; patients and clinicians were both responsible for actively listening and learning from one another when discussing goals. Patients described active listening as acknowledging both party's input and opinion. Learning from each other involved both parties working to understand the other party's perspective. Overall, participants believed that both active listening and learning is central to a 'collaboratively set goal.' For example, in response to a question about what makes a goal collaborative, one participant noted that:

"Talking to…your primary care doctor and letting him know what's going on, and…also having a doctor that… wants to listen to what you've got to say too…about your goals or what you want [to do]." [Focus Group 3, Participant 1]

In addition to listening and learning from each other, focus group participants articulated that clinicians were responsible for providing clear explanations. Participants noted that the

clinician needed to provide an understandable explanation of the goal's purpose so that patients could understand the reasons they were making changes, what they were working towards, and how to do so. When asked about what types of information are helpful to reach goals, one participant noted:

> *"What does this medication do, how does the [medication] work with the [insulin] and things just to know, that's the kind of stuff I need to know… That's helpful to me."[Focus Group 1, Participant 3]*

Another patient said:

> *"You should [sit] down before you leave the office, and you should have a clear understanding, and she, [the doctor], should have a clear understanding that you understand before you leave there."[Focus Group 4, Participant 2]*

The third theme identified was the importance of the sharing of ideas between the patient and clinician. Participants stated that setting a collaborative goal requires the input of both the patient and the clinician. Participants emphasized the importance of having an opportunity to provide input during goal discussions. To facilitate this, the clinician is responsible for giving the patient the opportunity to share important information and provide input, or the patient is responsible for offering their unsolicited input. For example, when asked about what does a collaborative goal setting discussion sound like, one participant stated:

> *"[My doctor] likes to see [what] my idea is first…we get together to try to get going." [Focus Group 3, Participant 2]*

Not only do patients need to have the opportunity to share their ideas, but they also felt they were responsible for having a say in the setting of the goal. By providing their input, patient's felt they were involved in the process. In response to being asked if they thought it would be possible to set a goal collaboratively with their doctor, one participant responded:

> *"Oh yeah, I'm gonna have some input because I mean, I'm not going in there blind and accept everything cause…I've learned stuff on the internet and I take it back to her, and I tell her about it." [Focus Group 1, Participant 1]*

A key part of sharing ideas mentioned by focus group participants is that the patient is responsible for being forthright about providing information, including events ongoing in their life, as well as values and/or beliefs. Patients noted this could include anything that may impact their health or impede their progress towards a goal. When asked if there is anything the clinician can do to help you share information with them, one patient noted:

> *"I think it is important to share if you can get it in. Things…that you talked about that it's important for them to know about: your private life, are you married, what do you do, what's your education, do you have children, all of those things do matter."[Focus Group 3, Participant 3]*

The fourth theme identified was the need to have a measureable objective. Ultimately, patients expressed the need to agree on a measurable objective with their clinician for a goal to be considered collaboratively set. While they clearly articulated this agreement as a central component of a collaborative goal setting process, participants repeatedly indicated that it was the clinician's responsibility, as the expert, to provide a target level for the patient to work towards. When asked what they consider to be collaborative when discussing health-related goals, one participant stated:

> *"I would like for my doctor to say, I want your sugar level to be 120 in the morning, 130 in the afternoon; all she…says is it's been high."[Focus Group 2, Participant 2]*

Similarly, another participant stated:

> *"[The doctor's] job is to have a goal for me."[Focus Group1, Participant 3]*

Although participants wanted the clinician to provide the target goal, they also noted discussions regarding the feasibility of goal achievement are the joint responsibility of patients and clinicians. This included the clinician, patient, or both discussing their thoughts on whether the goal was achievable or not. Participants thought it was important that they were given the

opportunity to share if they felt they could not reach a goal, or for the clinician to tell them if the goal they had set for themselves was too much of a stretch and the goal should be revised. For example, when asked what they thought was important for them to share when collaborating with their clinician, one participant said:

> *"It's important to share if you think there is something important about what the doctor said. [He said] try this, and maybe you can't do it because of your work hours. You need to let them know, you need to share that."[Focus Group 3, Participant 3]*

Finally, across focus groups, the importance of ongoing support for goal achievement was repeated noted as being central to collaborative goal setting. This support could come in a number of forms, including emotional, tangible, and instrumental. A participant noted that having emotional support, specifically in the form of encouragement, was a crucial part of the goal setting process and the responsibility of the clinician. Participants described how encouragement could help them make progress towards a goal. When asked about what they thought they would gain as a patient when collaborating with their clinician, a participant stated:

> *"If we really encourage people, maybe they will do better to eat right, or exercise, then it would help everybody."[Focus Group 4, Participant 4]*

In addition to wanting encouragement, participants also expressed that they wanted to be provided with tangible support; specifically, strategies for how to achieve the goal. Participants discussed that while they wanted to achieve a goal, they needed to know how to do so or to have a plan of action to follow, and it was the clinician's responsibility to provide this information. When asked what a collaborative discussion would sound like, one participant commented:

> *"I think it sounds something like, listen…my blood sugars are too high, we gotta get them down, and this is how we go about doing it"[Focus Group 1, Participant 1]*

In addition to emotional and tangible support, participants also discussed a need for follow-up, which is the responsibility of both the patient and the clinician. Participants stated that

they wanted to be held accountable for making progress towards the goal. For some individuals, this meant that during their next visit, the clinician would ask them about the goal to discuss progress as well as any complications or challenges in achieving the goal. Following up with the patient was seen as a way to get the patient to initiate changes necessary to reach the goal. When asked if they think it is possible to set a goal collaboratively with the doctor, one participant stated:

> *"I think it happens every time I go. They discuss [the goal] with you…they look at your progress and [if] you are going in the right direction, [or if] you [are] not going in the right direction."[Focus Group 3, Participant 3]*

Instrumental support is another responsibility of the clinician discussed by participants. Participants discussed that it was beneficial for them to have access to printed or other information to take home with them about their goal. Information could come in a variety of forms including pamphlets, websites, research articles, and laboratory results. Participants expressed that they wanted to know as much as they could, and were interested in receiving information that they might not be able to access on their own. When asked about what makes the goal discussion collaborative, a participant stated:

> *"I want to talk to my doctor about everything I try to be on the internet and everything to find out more information about different things that you can eat. [I] want to talk to [my] doctor to see what type of information he [has] to give."[Focus Group 3, Participant 2]*

Patient-Perceived Model of Collaborative Goal Setting

Using the identified themes, I constructed a conceptual model of patient-perceived collaborative goal setting. (Figure 2.1) Across the four focus groups, patients described collaborative goal setting as an ongoing process consisting of four distinct domains that occur within the context of a caring relationship. Within the context of an ongoing caring relationship, patients perceive collaborative goal setting has occurred when patients and clinicians (1) listen to

and learn from one another, (2) share ideas with each other, (3) reach agreement on a measureable objective, and when patients (4) receive support for goal achievement.

Discussion and Conclusion

Discussion

While the benefits of collaborative goal setting in health care have been generally well established, previous studies have not enabled an understanding of what makes a goal setting process collaborative from the patient's perspective. Results here indicate that patients perceive collaborative goal setting as a process that unfolds within the context of a caring relationship and is comprised of four domains: (1) listen and learn from each other; (2) share ideas honestly; (3) agree on a measurable objective; and (4) support for goal achievement. Within each domain, patients specified the responsibilities that belong to them and their health care provider.

Instead of being a communication transaction occurring within the confines of one clinical encounter, patients' perceived collaborative goal setting to be a multi-faceted process that occurs over time. This differs markedly from at least one previous depiction of collaborative goal setting in the clinical setting.[15] That framework described a more traditional decision-making model perspective and viewed collaborative goal setting as an event that occurred within the confines of a specific visit. Such a difference in perspective is reflected in patient perceptions that collaborative goal setting occurs within a caring relationship and by their articulation of the importance of support for goal achievement. The former is consistent with recent findings regarding patients' perspectives on shared decision making.[76] Furthermore, given 'support,' as described by patients, includes not only encouragement by the clinician, but also suggestions regarding achievement strategies and other supportive information as well as ongoing follow up, in many ways collaborative goal setting closely resembles traditional action planning.[25, 77, 78]

Patient reports of collaborative goal setting have repeatedly been linked to improved health outcomes.[12, 17, 18] As our results illustrate, patients perceive collaborative goal setting as including the provision of follow-up and ongoing emotional, tangible, and instrumental support. The benefits of social and other support have been consistently documented in chronic illness self-management,[79, 80] and it is well known that such illnesses impact a patient beyond the interactions that occur within the healthcare setting and thereby require support for ongoing self-management.[11] Participants in this study clearly articulated that they consider collaborative goal setting to include clinicians being an ongoing provider of support for goal attainment.

Findings from this study illustrate that patients articulate the need for both inclusion and advice in collaborative goal setting. While patients understood the need for them to have a voice when setting a collaborative goal for their health care, they also understood the limitations of their own knowledge. As such, patients wanted insight and input from their clinician regarding what an appropriate target level might be, as well as suggestions for strategies about how to achieve that target. In this sense, patients, in their own words, are articulating the ongoing challenge faced by clinicians: how to provide the advice patients want in a manner that supports autonomous motivation. In recent formulations of motivational interviewing, it is suggested that such advice can be incorporated via active reflections and by guiding the patient through the various choices they have to best improve their health and well-being.[81]

Given the time constraints faced by primary care physicians,[82] the challenge becomes how to integrate and facilitate the provision of support in an efficient manner. While some of this support may be able to be provided relatively quickly via follow-up office visits (e.g., verbal encouragement), other types of support articulated by patients as central to collaborative goal setting (e.g. achievement strategies) may be better provided via referrals to community-based

programs.[83] Regardless of how this support is provided, what seems to be key is that the support be perceived as fully integrated with the care being delivered by their clinician and that it be offered on a continual basis if the goal setting process is to be labeled as 'collaborative.'

Results here should be considered in the context of a number of limitations. Primary among these are the representativeness of those who participated in the focus groups. Although identified via a random sampling process, all focus group participants were primary care patients with diabetes receiving care from one safety net provider in central Virginia. Furthermore, only a relatively small proportion of those contacted agreed to participate in the focus groups, and an even smaller proportion eventually attended a focus group leading to potential selection bias. Those that chose to participate and attend a focus group session were possibly individuals with strong opinions on the health care they receive. They did, however, by sampling design, reflect both those patients with and without success in controlling their diabetes.

Conclusion

The results presented here shed light on the patient perspective of collaborative goal setting. Patients perceived collaborative goal setting to be more than a one-time transaction. Instead, they perceive collaborative goal setting as a process that occurs within a caring relationship and includes four domains: listen and learn from each other, share ideas, articulate a measurable objective, and support goal achievement. Within each domain, patients expressed active roles and responsibilities for both themselves and their clinicians.

Practice Implications

Our findings illustrate that collaborative goal setting cannot be considered within the confines of any one single discussion. Instead, collaborative goal setting, in the eyes of patients, is an ongoing transaction that occurs over time within the context of an ongoing, caring

relationship between the patient and their clinician. As such, both communication and workflow processes need to be developed that support not only the initiation of goal-oriented discussion in clinical practice, but also the provision of ongoing support and follow-up regarding goal attainment.

Table 2.1 – Example of Focus Group Guide Questions

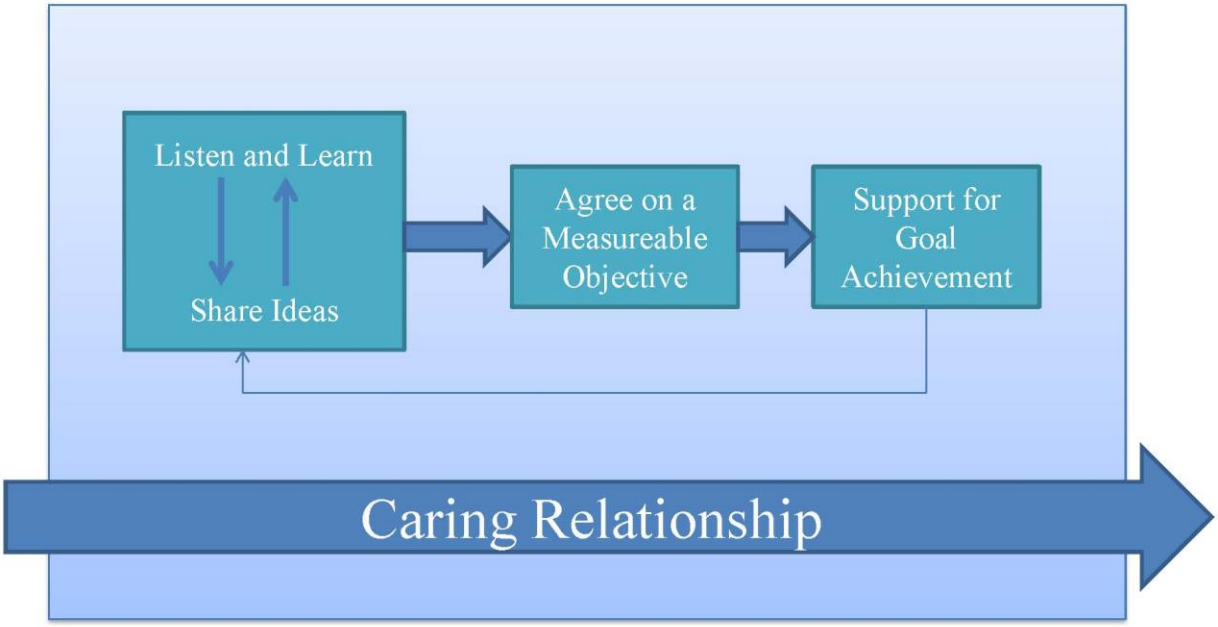
1. I am interested in learning more about the goal setting process. • When I say, "a goal was set collaboratively," what does that mean to you? • Some people prefer to set health-related goals collaboratively. In this situation, when a health-related goal is set, what do you think this conversation would sound like? • How do you share what you think about managing your health with members of the health care team?
2. Earlier, we discussed what a collaborative goal means to you. We would like to discuss goals that were set collaboratively and non-collaboratively. • Have you ever set a collaborative goal about your health during a visit to your doctor or health care team? How did you set this goal? What part of making this goal made it a collaborative goal? • Have you ever had a goal for your health that was set during an office visit, but wasn't set collaboratively? How was that goal set? Who set that goal and what did they say?
3. I am interested in learning about your goal setting process. • Some people like to work with their doctor/healthcare provider to set goals for their health. Others want to make their own goals or have the doctor/healthcare provider set the goals for them. How do you like to set your goals for managing your health? Why? • What is important to you to do or say when you are collaborating with your doctor/healthcare provider to set a health-related goal? • What problems do you think patients have when it comes to setting goals with healthcare providers/doctors?

Table 2.2 - Participant Characteristics

Socio-demographics	Individuals Contacted (N=168)	Attended a Focus Group (N=19)
Age	62.1 (SD=11.04)	58.2 (SD=9.51)
Gender		
Male	36%	32%
Female	64%	68%
Race		
White	16%	21%
African American	80%	79%
Other	4%	0%
Asian	1%	0%
Mean HbA1c Value	8.6% (SD=2.2)	8.3% (SD=2.3)

Hb=hemoglobin
SD= standard deviation

Figure 2.1 – Conceptual Model of Patient-Perceptions of Collaborative Goal Setting



Chapter 3/Paper 2: The construct validity of an instrument to measure collaborative goal setting in the care of patients with diabetes

Abstract

Introduction - Despite known benefits of patient-perceived collaborative goal setting, we have a limited ability to monitor this process in practice. We developed a measure of collaborative goal setting from the patient's perspective.

Design: Patients aged ≥ 40 years, receiving diabetes care from the Virginia Commonwealth University Health System (VCU-HS) were eligible for study inclusion. Previous results established four patient-identified domains of collaborative goal setting that occurred in an ongoing caring relationship: listen and learn from each other; share ideas; agree on a measurable objective; and provide support for goal achievement. Those findings were used to generate an initial pool of 6-11 survey items per domain. Cognitive interviews (n=4) and an expert panel were used to revise and refine items. The resulting 44 items were administered to patients with diabetes (n=400) via a mailed survey. Confirmatory factor analysis was used to evaluate instrument construct validity. Consistent with my conceptual model of collaborative goal setting, I tested a second-order factorial model where the five first-order factors were represented by the five conceptual domains of collaborative goal setting, and the second order being the collaborative goal setting construct.

Results: Among 259 returned surveys (64% participation rate), n=192 eligible individuals reported discussing a health-related goal with their clinician in the past six months. Results from the second-order factor analysis supported the proposed measurement structure of a 37-item measure of patient-perceived collaborative goal setting. Overall model fit of the first-order model was good ($\chi = 4366.13$, $p<.001$; RMSEA = .08). The internal consistency of the second-order model scales [caring relationship, listen and learn, share ideas, agree on a measurable objective, and support for goal achievement] was very high ($\alpha = .89$-$.94$) as was the reliability (Mcdonald's $\Omega = .819$).

Conclusions: The Patient Measure of Collaborative Goal Setting (PM-CGS) is a practical tool that has been shown to have construct validity. Future studies should evaluate the psychometric properties of this scale in relation to factors associated with patient outcomes.

INTRODUCTION

In recent years, there has been an increased focus on fostering patient engagement in the health care setting.[84] This is particularly true in the management of chronic diseases where self-management is known to play a critical role. One method of promoting patient engagement is the use of collaborative goal setting. Collaborative goal setting is a process in which both the patient and the health care provider play an active role in making decisions about the patient's health-related goals.[25] As such, the use of collaborative goal setting is now routinely recommended by many professional organizations, including the American Diabetes Association.[13, 85]

Previous studies have found that patient reports of collaborative goal setting with health care providers are associated with increased self-efficacy[16, 86, 87] and trust in their physician.[16, 34] Patient reports of engaging in collaborative goal setting has also been found to be associated with improved self-management behaviors and health outcomes, including improvements in Hemoglobin (Hb) A1c and blood pressure levels among patients with diabetes and hypertension.[15-17] However, despite recommendations for its use and the growing evidence of its benefits, we continue to have a limited understanding of how to measure and foster this process in practice.

Heisler et al. (2003) hypothesized that collaborative goal setting is a process that involves five domains: (1) sharing responsibility for making decisions, (2) mutually agreeing upon the goal, (3) discussing self-care management options, with the patient (4) sharing beliefs about illness treatment and (5) information about their life and values.[15] However, to my knowledge no study has empirically tested this conceptualization. Moreover, studies that have shown associations between patient-reported engagement in collaborative goal setting and improved outcomes have not enabled an understanding of the specific processes necessary for patients to

acknowledge their participation in a collaborative goal setting process. Instead, these prior studies have each relied on the Patient Assessment of Chronic Illness Care (PACIC), an instrument that leaves the definition of collaborative goal setting open to the respondents' individual interpretations.[25]

We have previously used qualitative research methods to identify what needs to occur for a goal setting process to be considered collaborative in the eyes of patients with diabetes.[88] Findings from that study indicated that patients conceptualize collaborative goal setting as a multi-dimensional process that unfolds over time within the context of a caring relationship with their clinician.[88] Similar to how Heisler et al. (2003) conceptualized the process, patients identified multiple domains of collaborative goal setting discussions that occurred within a caring relationship: (1) listen and learn from each other, (2) share ideas, (3) agree on a measurable objective, and (4) support for goal achievement.

The primary objective of this study was to use results from this latter conceptualization of collaborative goal setting to develop a patient-reported measure of collaborative goal setting that could be used for monitoring and evaluating the occurrence of collaborative goal setting among patients with diabetes. Here, I describe the development, refinement, and evaluation of items to be used in a patient-reported measure of collaborative goal setting in the context of diabetes care. I also report the types of goals patients with diabetes report discussing with their clinicians and the extent to which they report setting those goals via a collaborative goal setting process with their clinician.

RESEARCH DESIGN AND METHODS

Sample

The target population for the development of the Patient-reported Measure of Collaborative Goal Setting (PM-CGS) was patients currently receiving diabetes care within the Virginia Commonwealth University Health System (VCU-HS). Eligible participants were aged 40 years or older with an outpatient visit to a primary care clinic or endocrinologist associated with their ongoing diabetes care between August 2012 and August 2013. Diabetes was defined as having any outpatient encounter with an associated diagnostic code for diabetes (i.e. ICD-9 = 250 or 366.41, 357.2, 362,0). Patients less than 40 years of age and those with gestational diabetes were excluded. Patients were identified using the structured data contained within the electronic health record at VCU-HS.

Measure Development

Measure development was divided into three consecutive phases. In the first phase of the study I developed survey items for potential inclusion in the PM-CGS. Items developed were based on findings from a previously conducted qualitative study that utilized focus groups to explore patient perceptions of collaborative goal setting in diabetes care.[88] The inclusion criteria for that study were virtually identical to ones used in the current study. The one exception was that for the focus group study patients had to have had an outpatient visit in the previous month to enable them a recent office visit experience upon which to draw. That study resulted in a conceptualization of collaborative goal setting as including five domains: (1) listen and learn from each other, (2) share ideas, (3) the context of a caring relationship, (4) agree on a measurable objective, and (5) support for goal achievement.[88] Domain descriptions appear in Table 3.1. For each of these domains I developed six to eleven survey items to which patients

could respond with a 5-point Likert response format ranging from 1 (strongly disagree) to 5 (strongly agree). In total, 77 items were developed.

In the second phase of the study, the initial pool of 77 items was revised and refined by incorporating input from an expert panel and by conducting cognitive interviews. The expert panel included a psychometrician, a primary care physician, a health communication specialist, and a health psychologist. Input from the expert panel was used to revise question wording and eliminate redundant items (n=10). The remaining 67 items were tested via patient cognitive interviews. Cognitive interviews used the "concurrent think aloud" method[89, 90] and were conducted among a convenient sub-sample of original focus group participants from our qualitative study: n=2 males (one black and one white), and n=2 females (one black and one white). These interviews were used to pilot test the survey for comprehensibility, relevance, and to ensure items reflected themes identified from the focus groups. Participants were asked to provide their thoughts as they completed the questionnaire and responses were probed for further insight.[90] Cognitive interviews took on average thirty minutes to complete (range 25 to 40). Based upon feedback from the cognitive interviews, the initial pool of items was further reduced (n=23) resulting in a total of 44 items for consideration in the PM-CGS.

In the third phase of the study, the 44-item PM-CGS was administered to a sample of N=400 patients with diabetes. The SPSS v.21 random number generator was used to identify the 400 patients from all eligible individuals identified within the VCU-HS electronic health record system. Individuals who had previously participated in a focus group were excluded from this phase of the study. A letter of study introduction and a survey were mailed to patients. (Appendix B) The letter of study introduction described the study in general terms, asked that the patient complete the enclosed questionnaire, and included a $2.00 bill. Survey administration

followed a Dillman approach[91]: two weeks after the initial mailing, non-respondents received a reminder postcard; after an additional two weeks, non-respondents were sent another survey packet. Questionnaires and postcards were mailed using first class postage, personalized communication, with stamped returned envelopes enclosed, each of which has been shown to improve response rates.[92, 93] Patients who returned a survey received a $20 gift card to a local retail store. Returned surveys were entered into SPSS with optical mark recognition using Remark OMR™.

The survey included the 44 collaborative goal setting items, as well as items that collected information on the patient's socio-demographic characteristics, depressive symptoms as measured by the PHQ-2,[94] overall health status[95] and health behaviors such as smoking.[96] (Appendix B) Respondents were also asked to identify the context of their goal-related discussion(s) by indicating the topic(s) of any health-related goal(s) they discussed with their health-care provider in the past 6 months. Respondents were able to select one or more provided topics (i.e. to lose weight, to exercise more, control clinical levels, eat healthier, or stop smoking) and/or to write in a topic under an "other" response option. The study was approved by the Virginia Commonwealth University Institutional Review Board.

Statistical Methods

Descriptive statistics were used to describe the goal topics patients reported discussing with their clinicians. Reported topics were grouped into two categories: lifestyle [i.e. weight loss, exercise, eating healthier and smoking cessation] and clinical [i.e. improving blood pressure, cholesterol, or HbA1c]. Upon completion of measure assessment, differences in patient reports of collaborative goal setting by goal type were tested with ANOVA.

Confirmatory factor analysis was used for measure assessment. Prior to conducting the

confirmatory factor analysis, survey data were evaluated for missing data. While some item non-response was present for each question, less than 5% were missing for any one item. We therefore used full information maximum likelihood estimation to incorporate all available data when conducting analyses.[97] Consistent with our conceptual model of collaborative goal setting, we tested a second-order factorial model. (Figure 3.1) This model used a multi-dimensional representation of collaborative goal setting where the five first-order factors were represented by the five conceptual domains of collaborative goal setting as previously identified: (1) listen and learn from each other, (2) share ideas, (3) caring relationship, (4) agree on a measurable objective, and (5) support goal achievement. Mplus version 6 was used to estimate the model. Hu and Bentler (1999) criteria were used to evaluate model fit.[98] Structural equation modeling was used to evaluate differences in the report of collaborative goal setting by goal topic and by the health care provider with whom they discussed the goal. McDonald's Omega coefficient was used to determine how well the items within each of the five domains measured the same latent variable, collaborative goal setting.[99]

RESULTS

Sample Characteristics

A total of 259 individuals (64% response rate) completed the survey.[100] Of those, 20 individuals were excluded (n=19 did not report having diabetes and n=1 reported having gestational diabetes). Among the remaining 239 individuals, n=192 reported discussing a health-related goal with their clinician in the past six months and were included in the current analyses. The mean age of eligible survey respondents was 60.1 years (SD=9.36; range 41-89); 71% were women and 67% were Black. (Table 3.2) The majority had graduated from high school (69%) and was insured (92%). A total of 32% were currently married, and 45% had an annual income

below $15,000.

The majority of goals reported by respondents centered on improving blood pressure, cholesterol, or Hemoglobin (Hb) A1c control (56%), followed by weight loss (40%) and an increase in exercise (39%). (Table 3.3) In total, 31% of the sample reported discussing a lifestyle goal, 31% reported discussing a clinical goal, and 38% reported discussing both.

Survey Measure Assessment

The 44 collaborative goal setting survey items are listed in Table 3.4. Seven items had standardized factor loadings onto their respective domain considerably lower than the other items (i.e. factor loadings less than 0.40) indicating that they did not appropriately measure the domain. These seven items (as indicated in Table 3) were omitted from consideration, resulting in a 37-item final model.

The overall fit of the 37-item model was good (χ^2=4366.13, p<.001; RMSEA = .07). Each of the remaining items had significant (p<.001) loadings onto their respective domains. These first-order factors had loadings that ranged from 0.57-0.93 (mean loading = 0.78). (Table 3.4) Within the second-order factorial model, where the concept of collaborative goal setting is represented by the five domains, each of the five first-order factors is significantly (p<.001) and strongly (i.e. standardized factor loadings ranging from 0.82 to 0.95) associated with the construct of collaborative goal setting.(Table 3.5) The internal consistency of each of the five domains was high (range .894-.940), as was the level of consistency for the second-order factor collaborative goal setting ($\alpha = 0.927$). McDonalds Omega was estimated and indicated a high level reliability within the measure ($\Omega = .819$).

Collaborative Goal Setting by Goal Topic

No statistically significant differences were found when examining patient reports of

engaging in collaborative goal setting by goal type. (Table 3.6)

DISCUSSION

Among a sample of patients receiving outpatient care for their diabetes, a multi-dimensional measure of collaborative goal setting was created. Consistent with an a priori conceptualization of collaborative goal setting,[88] as well as other previous depictions,[15] the measure consists of 37 items that span five domains: (1) listen and learn from each other, (2) share ideas, (3) caring relationship, (4) articulate measureable objective, and (5) support for goal achievement. Not only was the measure found to have high internal consistency ($\alpha = .927$), but it was also found to have a high level of reliability ($\Omega = .819$).

The PM-CGS builds upon the initial conceptualization put forth by Heisler (2003).[15] Consistent with Heisler (2003), the conceptualization of collaborative goal setting tested here depicts collaborative goal setting as a communication process in which patients and their clinicians share ideas and information, and reach agreement on a goal or target level.[15] However, our prior qualitative findings[88] lead us to test the appropriateness of adding that these interactions needed to occur within the context of a caring relationship with the clinician, and that they required ongoing support for a goal to be achieved. Results from the measurement assessment analyses support the appropriateness of including both these domains as they were significantly associated with the overall collaborative goal setting construct. The PM-CGSM evaluates collaborative goal setting as an act that both the patient and the health care provider are responsible for, and is a comprehensive, multi-dimensional assessment of the doctor-patient interaction during the clinical encounter that leads patients to report collaborative goal setting.

The PM-CGS was initially developed for use among patients with diabetes. This was an ideal population with whom to develop and test this measure because of the high level of self-

management required in diabetes care. Thus, patients with diabetes have a high likelihood of having goal discussions from which to reflect upon. However, it is important to note that collaborative goal setting is not a concept unique to the diabetes population. In fact, collaborative goal setting is a practice that is promoted for use in chronic illness care [13, 85] and the potential merits have been posited for a number of illnesses.[17, 101]

There are a number of strengths and limitations associated with this study. One of the limitations is that the sample was limited to patients receiving care from VCU-HS. While participants were representative of patients receiving care at VCU-HS, they may not be reflective of populations in other health care settings. Another limitation of this study is the small sample size for the development of a measure. While there was a high response rate, only 192 respondents (74%) reported engaging in a goal oriented discussion. However, even with a small sample size, the effect sizes indicated that the PM-CGS was a highly reliable measure of collaborative goal setting. Finally, while my conceptual framework highlights the importance of collaborative goal setting occurring over time, the cross-sectional design of my research precluded exploration of this dimension of collaborative goal setting.

One of the main strengths of this study was that it included a random sample of the target population. VCU-HS has a large number of individuals who receive diabetes care on an outpatient basis, thus making it feasible to randomly select 400 patients who are representative of the population. Another strength of this study was the high response rate of participants. VCU-HS is often a difficult population to recruit from due to the large amount of individuals with lower levels of education and income. However, I was able to obtain a 64% response rate. Furthermore, the readability of the measure was appropriately suited for the demographic of interest, and was written at an 8th grade reading level.

Conclusions

Findings from this study provide preliminary support for the construct validity of the PM-CGS among patients with diabetes. Not only was the overall fit of the model good (χ^2=4366.13, p<.001; RMSEA = .07), but the measure was shown to have high levels of both internal consistency (α = .927) and reliability (Ω = .819). As such, the PM-CGS appears to be appropriate for assessing the multiple dimensions that make up the collaborative goal setting construct.

Practice Implications

Future research should focus on adapting the PM-CGS to other patient populations under chronic illness care and externally validating the instrument by predicting health outcomes like trust, self-efficacy, and self-management. By doing so, we will be able to fully understand the pathways by which collaborative goal setting impacts health outcomes.

Table 3.1 – Scale Definitions

Five Components of Collaborative Goal Setting	Definition
Listen and Learn from Each Other (items 1-9)	Setting a goal is not one-sided; not only do patients need to listen and learn from their physicians, but physicians need to listen and learn from patients
Share Ideas (items 10-16)	The physician shares his or her ideas but also gives the patient the opportunity to share, or the patient initiates and give his/her input
Caring Relationship (items 17-24)	Physicians have a good bedside manner, are compassionate, and are sensitive to patient needs
Agree on a Measureable Objective (items 25-29)	Patients agree on a measurable objective with their physician including the provision of a target level
Support for Goal Achievement (items 30-37)	The provision of support in a number of forms: emotional, tangible, or instrumental

Figure 3.1 – First and Second Order Factorial Model

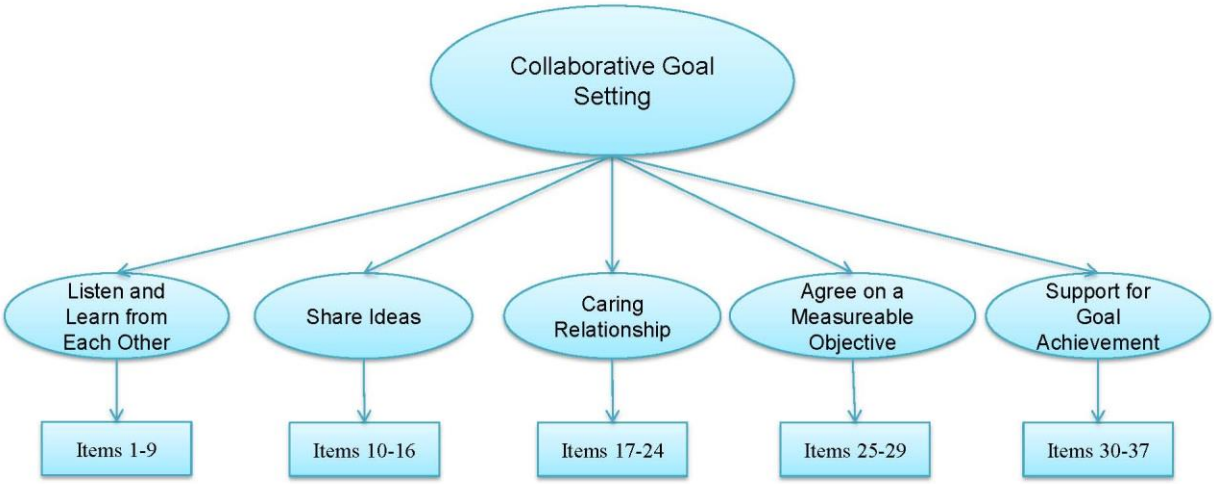


Table 3.2 – Sample Characteristics (n=192)

Socio-Demographic Factors	
Age	60.1 (SD=9.36)
Gender	
Male	29%
Female	71%
Education	
Grades 1-8	9%
Grade 9-11	22%
HS Graduate or GED	25%
College 1-3 years	25%
College Graduate	19%
Marital Status	
Currently Married	32%
Never Married	24%
Separated	9%
Divorced	22%
Widowed	13%
Race	
White	27%
African American	67%
White & American Indian	6%
Hispanic or Latino	3%
Employed	25%
Insured	92%
Income	
$0-$14,999	45%
$15,000 to $74,999	42%
$75,000 or more	12%
Self-Reported Health Status Factors	
Excellent	2%
Very Good	17%
Good	38%
Fair	33%
Poor	10%
Current Smokers	18%
Depressive Symptoms	47%

Table 3.3 – Goal Topics Discussed by Participants

Goal Topic	Percent
Weight loss	40%
Increase exercise	39%
Improve blood pressure, cholesterol or HbA1c	56%
Eat healthier	27%
Stop smoking	14%
Other	3%

Note: Participants were able to select multiple goals.

Table 3.4 – Confirmatory Factor Analysis (n=192): Individual Survey Items with the Five Domains of Collaborative Goal Setting

First-Order Factors	Factor Loadings
Factor A: Listen and Learn from Each Other	
Item 1: I asked my doctor any questions I had	0.77
Item 2: My doctor asked me if I had any concerns	0.73
Item 3: My doctor explained the reasons for the goal	0.77
Item 4: I learned important things from my doctor	0.70
Item 5: My doctor listened to what I had to say	omitted
Item 6: My doctor and I discussed the reasons for the goal	0.80
Item 7: I listened to what my doctor had to say	0.64
Item 8: I told my doctor important things about me	0.61
Item 9: I told my doctor about any concerns I had	0.63
Item 10: My doctor explained things in a way that was easy to understand	omitted
Item 11: My doctor gave me the opportunity to ask any questions I had	0.72
Factor B: Share Ideas	
Item 12: I made sure my doctor knew about things that were important to me	0.66
Item 13: My doctor asked for my input	omitted
Item 14: I told my doctor about important things in my life	0.66
Item 15: My doctor shared his/her ideas with me	0.80
Item 16: I was interested in my doctor's ideas	0.73
Item 17: My doctor seemed interested in my ideas	omitted
Item 18: My doctor provided important medical information to me	0.77
Item 19: I shared my ideas with my doctor	0.77
Item 20: I felt confident my doctor understood what was important to me	0.90
Factor C: Caring Relationship	
Item 21: My doctor treated me as a person	0.78
Item 22: My doctor took take time to understand what was important to me	omitted
Item 23: I respected my doctor's opinions	0.93
Item 24: My doctor showed he/she cared about me as a person	0.93
Item 25: My doctor respected my opinion	0.83
Item 26: My doctor was honest with me	0.90
Item 27: My doctor spent enough time with me	0.81
Item 28: I showed my doctor that I cared about achieving the goal	0.74
Item 29: I was honest with my doctor	0.72
Factor D: Agree on a Measurable Objective	
Item 30: The goal set was achievable	omitted
Item 31: I felt good about the goal	0.79
Item 32: My doctor helped me understand what the specific goal is	0.84
Item 33: I had confidence that I could achieve the goal	0.72
Item 34: My doctor and I agreed on the specific goal that was set	0.82
Item 35: My doctor and I discussed the potential specifics of the goal	0.79
Factor E: Support for Goal Achievement	

Item 36: My doctor gave me information I could take home about the goal	0.57
Item 37: I was confident I knew how to achieve the goal	omitted
Item 38: I told my doctor I felt like I could achieve the goal	0.78
Item 39: My doctor and I discussed strategies for achieving the goal	0.89
Item 40: I was comfortable discussing any challenges I might have achieving the goal	0.74
Item 41: My doctor made me feel like I could achieve the goal	0.88
Item 42: My doctor and I came up with a strategy for how to achieve the goal	0.90
Item 43: My doctor checked to make sure I understood the goal	0.88
Item 44: My doctor described how to achieve the goal	0.90

Note: All factor loadings are significant ($p<.001$). Standardized parameter estimates are shown.

Table 3.5 – Confirmatory Factor Analysis (n=192): Five Domains of Collaborative Goal Setting with the Overall Construct of Collaborative Goal Setting

First-Order Factors	Factor Loadings	Cronbach's Alpha
Factor 1: Listen and Learn	0.82	.898
Factor 2: Share Ideas	0.91	.907
Factor 3: Caring Relationship	0.90	.935
Factor 4: Agree on a Measurable Objective	0.95	.894
Factor 5: Support for Goal Achievement	0.90	.940

Note: All factor loadings are significant ($p<.001$). Standardized parameter estimates are shown. The second-order factor has Cronbach's alpha of .927 and McDonald's omega of .819.

Table 3.6 – ANOVA Results for Goal Type by Domain

Domains	Overall	Lifestyle Only (n=55)	Clinical Only (n=56)	Multiple Goals (n=69)	p-value
Listen & Learn	4.59 (.60)	4.56(.82)	4.56(.51)	4.64(.48)	.409
Share Ideas	4.41(.81)	4.33(.95)	4.43(.66)	4.42(.80)	.716
Caring Relationship	4.65(.59)	4.61(.77)	4.59(.52)	4.71(.51)	.308
Agree	4.36(.79)	4.30(.90)	4.34(.68)	4.42(.81)	.449
Support	4.31(.87)	4.27(.95)	4.21(.77)	4.38(.92)	.313
Total Score	4.46(.64)	4.41(.79)	4.40(.55)	4.55(.58)	.181

Chapter 4/Paper 3: External validity of the patient measure of collaborative goal setting in relation to pathways for improved outcomes

Abstract

Objective: The Patient Measure of Collaborative Goal Setting (PM-CGS) is a newly developed tool for evaluating the use of collaborative goal setting in clinical practice. The purpose of this study is to assess the external validity of the PM-CGS by assessing the pathways through which collaborative goal setting is associated with improved outcomes as reported with the PM-CGS.

Methods: In September, 2013 a mailed survey was sent to n=400 patients aged 40 years and older receiving diabetes care from the Virginia Commonwealth University Health System (VCU-HS). Surveys included the PM-CGS, and previously validated measures of self-efficacy, trust in the physician, and self-management behaviors. Structural equation modeling was used to test the pathways by which collaborative goal setting impacts self-management behaviors.

Results: A total of 259 individuals returned the survey (64% response rate) and n=192 reported a recent goal oriented discussion with their clinician and were eligible for inclusion in the current analyses. While three of the hypothesized pathways were statistically significant, the only pathway that was found to be significant was the relationship between collaborative goal setting and self-management, which was partially mediated by self-efficacy ($p<.05$). After controlling for a variety of socio-demographic characteristics, the partial mediation model with self-efficacy was no longer significant ($p=.055$), however, the direct effects remained significant: self-management and collaborative goal setting ($p<.001$) and self-efficacy ($p<.001$), as well as self-efficacy on collaborative goal setting ($p<.05$).

Conclusion: The findings provide evidence of the external validity for the pathways by which collaborative goal setting impacts self-management behaviors. Further research is needed to test the methods to improve patient reports of collaborative goal setting.

Introduction

Patient engagement is now routinely advocated as a means to positively influence patient outcomes.[102] One method used during clinical encounters to promote patient engagement is collaborative goal setting. Collaborative goal setting is a process that involves both the patient and physician working together to set a health-related goal. Collaborative goal setting is an integral component of the Chronic Care Model[11] and the American Diabetes Association (ADA) and others advocate for its use in routine clinical care.[13, 85]

Not only does the act of collaborative goal setting encourage patients to become an active participant in their office-based receipt of health care, but it also helps foster ongoing engagement in necessary self-management behaviors once patients leave the office. Prior research has found that patient reports of collaborative goal setting are associated with health outcomes through a number of pathways.[16, 17] Increases in the amount of trust a patient has in their physician, as well as higher levels of confidence in their self-management capability, have been shown to lead to improvements in a patient's Hemoglobin (Hb) A1c control.[16]

I recently developed a multi-dimensional measure of collaborative goal setting called Patient Measure of Collaborative Goal Setting (PM-CGS). This 37-item measure was developed to both identify and assess the multiple components of collaborative goal setting during clinical encounters by patients with diabetes. While this measure has been shown to appropriately capture the multiple dimensions of collaborative goal setting,[94] its use has not yet been validated in regards to its relationship with patient outcomes.

The purpose of this paper is to evaluate the external validity of the PM-CGS using the previously hypothesized pathways through which engagement in collaborative goal setting is thought to impact self-management behaviors.

METHODS

Recruitment and Respondents

Study eligible patients were those aged 40 years or older receiving diabetes care at Virginia Commonwealth University Health System (VCU-HS). Eligible participants were identified using the structured data available within the electronic health record at VCU-HS. Patients with an outpatient visit to a primary care clinic or endocrinologist between August 2012 and August 2013 were identified. Diabetes was defined as having any outpatient encounter with a n associated diagnostic code for diabetes (i.e. ICD-9 = 250 or 366.41, 357.2, 362.0). Patients less than 40 years of age and those with gestational diabetes were excluded. Among eligible patients I used the SPSS v.21 random number generator to identify a random sample of 400.

Sample patients were mailed a survey packet that included a letter of study introduction, a $2.00 bill, and the questionnaire. The letter of study introduction described the study, asked that the patient complete the enclosed questionnaire, and informed them that survey responders would receive a $20 gift card for a local retail store. (Appendix B) Survey administration followed a Dillman approach[91]: two weeks after the initial mailing, non-respondents received a reminder postcard; after an additional two weeks, non-respondents were sent another survey packet. Questionnaires and postcards were mailed using first class postage, personalized communication, and stamped returned envelopes. To be included in current analyses, respondents had to report engaging in a health-related goal discussion in the previous six months with a health care provider.

Measures

The questionnaire included the PM-CGS,[103] the Perceived Competence Scale,[104] the Trust in Physician Scale,[105] and a measure of diabetes self-management,[106] each of which is

described below. The survey also included items specific to the patient's socio-demographic characteristics. Patient socio-demographic characteristics included the patient's age, race, gender, marital status, employment status, income, and level of education achieved.

Patient Perceptions of Collaborative Goal Setting

The PM-CGS is a 37-item measure used to assess the extent to which patients report engaging in collaborative goal setting with their health care provider in the past six months.[103] Measure responses depict participation in collaborative goal setting within five domains: (1) listen and learn from each other, (2) share ideas, (3) caring relationship, (4) agree on a measurable objective, and (5) support for goal achievement. For each domain, there are between six and eleven survey items for which respondents express the degree to which they agree with the statement [i.e. I asked my doctor any questions I had] using a 5-point scale ranging from strongly disagree (1) to strongly agree (5). Higher scores represent patient reports of a collaborative goal being set. The five domains of the PM-CGS are used to create a factor (latent variable). The reliability and internal consistency of this factor has been previously confirmed: the Cronbachs' Alpha showed a high level of consistency ($\alpha = 0.927$) and McDonalds Omega indicated a high level of reliability ($\Omega = 0.819$). For descriptive purposes, the average of all 37-items was calculated for an overall score of collaborative goal setting.

Perceived Competence for Diabetes

The Perceived Competence for Diabetes scale is a 4-item questionnaire designed to assess constructs from the self-determination theory.[104] This scale assesses a participant's feelings in regards to management of glucose levels among patients with diabetes based upon how true the four statements [i.e. I feel confident in my ability to manage my diabetes] are using

a 7-point scale [1 – not at all true, 4 – somewhat true, 7 – very true]. The participant's self-efficacy score is calculated by averaging the responses for the four items.

Trust in Physician Scale

The trust in physician scale is an 11-item measure designed to assess the quality of the patient-physician relationship.[105] This scale assesses the degree to which patients trust their physician by asking them to express their level of agreement with statements [i.e. I doubt that my doctor really cares about me as a person] based upon a five point scale [1 – totally disagree, 2 – disagree, 3 – neutral, 4 – agree, and 5 – totally agree]. For scoring, the sum of all 11 items are computed and then transformed to a 0-100 scale.[105]

Summary of Diabetes Self-Care Activities Measure

Self-management scores were assessed using a 10-item measure that is widely used in diabetes adherence.[107] The Summary of Diabetes Self-Care Activities (SDSCA) measure is a brief, reliable and valid self-report measure of diabetes self-management activities.[106] The five domains of the SDSCA include: general diet, specific diet, exercise, blood sugar testing, and foot care. Each domain contained two questions regarding patient reports of self-management behaviors. Item responses were determined by patients selecting the number of days in the past week they engaged in a number of behaviors [i.e. How many of the last seven days have you followed a healthful eating plan] related to each of the five sections. For each of the domains, the mean number of days was calculated for the total score per domain.

Statistical Methods

Structural equation modeling (SEM) was used to test the pathways through which collaborative goal setting impacts self-management behaviors. Figure 4.1 depicts the conceptual

model tested. Collaborative goal setting and self-management variables are specified as latent variables in the SEM (Figure 4.2). Prior to model fitting, one-factor model was used to represent each collaborative goal setting domain. Subsequently, five collaborative goal setting domain scores, calculated as the sum of item responses, were used as indicators of the latent collaborative goal setting variable in the SEM. Similarly, five domain scores of self-management scale scores were used as the indicators of the latent self-management variable in the SEM. As depicted in Figure 4.2, self-efficacy and trust were used as observed variables mediating the relationship between collaborative goal setting and self-management. The model was tested both with and without the presence of covariates. Mplus v.6 was used to run all analyses.

RESULTS

Sample Characteristics

Among the N=400 patients mailed the survey, 259 were returned resulting in an overall response rate of 64%. A total of 192 participants reported discussing a health-related goal with their clinical team in the past six months, and thus were eligible for inclusion in the current study. On average, survey respondents were 60 years of age (SD=9.4), predominately female (71%), and self-identified as Black (67%). (Table 4.1) Patients of varying education levels participated in the study, with the majority having a high school diploma (25%) or some college education (25%).

Results from the one-factor solutions for all five domains of CGS appear in Table 4.2. These results supported the uni-dimensional representations of all five domains. On average, patients endorsed that the goal setting process they had used with their clinician over the past six months was collaborative (mean = 4.47, range 1 [strongly disagree] to 5 [strongly agree]). (Table

4.2). Participants were found to report high levels of trust in their physician (mean=85.02, SD=14.14, range 32.7 to 100.0), as well as high levels of self-efficacy (mean = 5.80, SD=1.51). On average, patients engaged in self-management behaviors in more than half of the days in a week: general diet mean=4.91 (SD=1.74), specific diet mean = 4.22 (SD=1.51), exercise mean = 3.72 (SD=2.23), blood sugar testing mean = 5.04 (SD=2.42), and foot care mean = 4.37 (SD=1.43).

Relationship between Patient Perceptions of Collaborative Goal Setting and Self-Management

The overall fit of the unadjusted model was good (χ^2 = 4827.38, p<.001; RMSEA = .07). Standardized factor loadings for the PM-CGS ranged from 0.83 to 0.94. Three of the pathways tested within the model were found to be statistically significant. Collaborative goal setting was significantly associated with increased self-efficacy (p<.03) as well as with self-management behaviors (p<.001). Furthermore, self-efficacy was significantly associated with an increase in a patient's self-management behaviors (p<.001). Patient reports of physician trust were not significantly associated with either collaborative goal setting or self-management behaviors. Standardized parameter estimates can be found in Figure 4.2.

In addition to testing the pathways of significance, a mediation model was also tested as increased reports of collaborative goal setting was shown to be significantly associated with increased self-efficacy, which was significantly associated with increased self-management behaviors. The mediation model that was tested, therefore, was whether the relationship between collaborative goal setting and self-management was mediated by the patient's self-efficacy. Results (p<0.05) supported that the relationship between collaborative goal setting and self-management was partially mediated by self-efficacy.

After controlling for patient socio-demographic characteristics, the partial mediation model with self-efficacy was no longer significant (p=.055). However, the direct effects remained significant: both collaborative goal setting and self-efficacy were significantly ($p<0.001$) associated with improved self-management, and collaborative goal setting ($p<.05$) remained significantly associated with improved self-efficacy. In addition, a positive relationship between collaborative goal setting and a patient's trust in their physician also became significant ($p<.05$).

Covariate effects are shown in Table 4.3. Older patients were more likely to report engaging in collaborative goal setting, have a high level of self-efficacy, and more likely to trust in the physician. Patients who were black were less likely than white patients to report engaging in collaborative goal setting. Compared to patients with a college degree, patients with a high school degree were less likely to report engaging in collaborative goal setting. Finally, patients with lower levels of education were less likely to have a high level of trust in their physician and to report engaging in self-management behaviors.

DISCUSSION

Results from this study provide evidence of the external validity of the PM-CGS for measuring the occurrence of collaborative goal setting among patients with diabetes. I found that collaborative goal setting as measured by the PM-CGS was positively associated with improved self-management behaviors ($p<.001$) as well as support for the hypothesis that collaborative goal setting as measured by the PM-CGS may further be associated with improved self-management by improving patients' self-efficacy. Furthermore, once patient socio-demographic characteristics were controlled, patient reports of collaborative goal setting as reported by the PM-CGS were also associated with improved physician trust.

Previous studies have shown that the relationship between collaborative goal setting and hemoglobin (Hb) A1c is mediated by both self-efficacy and the amount of trust a patient has in their physician.[16] Results here support a partially mediated model between collaborative goal setting and self-management through self-efficacy, but not one through trust. As self-management is generally considered central to HbA1c control, it may be that while the relationship between self-efficacy and HbA1c is mediated by self-management, the relationship between trust and HbA1c is not.

The well-established relationship between self-efficacy and self-management behaviors is central to chronic care management.[32, 43, 56, 60, 61] Efforts to improve self-efficacy have included education programs,[55] coping skills training,[108] and peer led groups.[109] While these efforts have generally been successful, it still requires patients to engage in supplemental programming in addition to their standard care.[110] Our results imply that the use of office-based collaborative goal setting may be an effective way to foster self-efficacy and thereby may provide an efficient and effective method of impacting self-efficacy and thus self-management behaviors. However, collaborative goal setting is a process that occurs during regularly scheduled office visits and can be conducted opportunistically and within the confines of existing appointments, thereby avoiding additional time burdens to patients.

Findings presented here indicated that the PM-CGS goes beyond measuring collaborative goal setting, as it also influences both proximal (i.e self-efficacy) and intermediate outcomes (i.e. self-management). As such, the external validity of the PM-CGS can be generalized to factors associated with improved health outcomes. Due to the relationship previously shown between self-management and clinical outcomes (i.e. HbA1c), it can be posited that collaborative goal

setting also indirectly impacts clinical and other health outcomes (i.e. quality of life and emotional well-being).

This study has a number of limitations including the possibility that findings may not be generalizable to other patient and clinic settings. This study population reflected those receiving diabetes care from one safety net provider in central Virginia. As such, although the population was largely insured, the majority was of relatively low socio-economic status as evidenced by their educational attainment and income. Furthermore, despite the relatively high response rate for the survey, only 74% of respondents reported engaging in a recent goal setting process with their clinician. The result was that only 192 respondents were eligible for inclusion in the current analyses. Thus, while I was able to uncover robust findings regarding the external validity of the collaborative goal setting measure, power may have precluded the detection of other important relationships. While there were limitations to the study, there were also a number of strengths. These include the use of a random sample of patients and a relatively high response rate (64%) for a mailed survey.

Practice Implications

My findings have a number of implications for future research. While collaborative goal setting, as measured by the PM-CGS, was found to have a positive impact on self-management behaviors, it has not been tested in relation to either clinical or patient-centered outcomes. Future research should focus on further examining the pathways through which collaborative goal setting as measured by the PM-CGS impacts a variety of clinical and other outcomes.

Figure 4.1 – Pathway from Collaborative Goal Setting to Self-Management

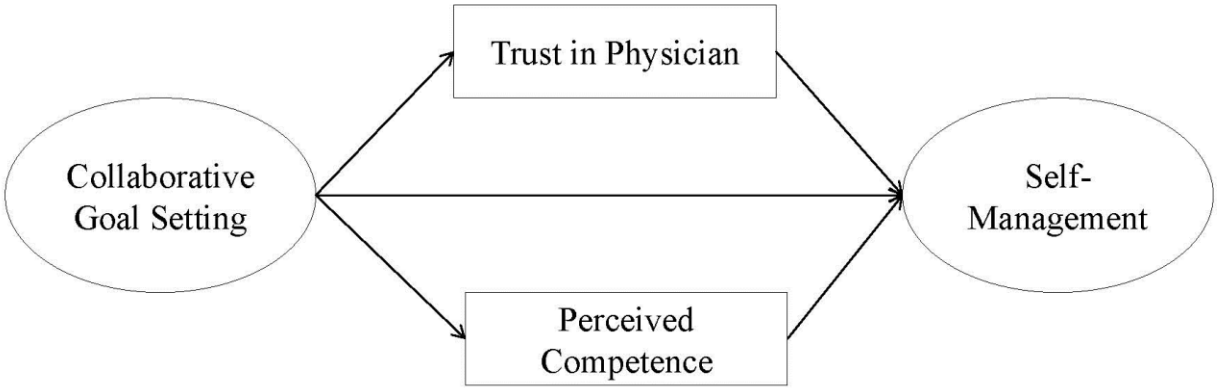


Table 4.1 – Sample Characteristics (n=192)

Socio-Demographic Factors	
Age	60.1 (SD=9.36)
Gender	
Male	29%
Female	71%
Education	
Grades 1-8	9%
Grade 9-11	22%
HS Graduate or GED	25%
College 1-3 years	25%
College Graduate	19%
Marital Status	
Currently Married	32%
Never Married	24%
Separated	9%
Divorced	22%
Widowed	13%
Race	
White	27%
African American	67%
White & American Indian	6%
Hispanic or Latino	3%
Employed	25%
Insured	92%
Income	
$0-$14,999	45%
$15,000 to $74,999	42%
$75,000 or more	12%
Self-Reported Health Status Factors	
Excellent	2%
Very Good	17%
Good	38%
Fair	33%
Poor	10%
Current Smokers	18%
Depressive Symptoms	47%

Table 4.2 – PM-CGS, Self-Efficacy, Trust in Physician, and Self-Management

	Mean (SD)
PM-CGS	
Listen and Learn	4.61(SD=0.61)
Share Ideas	4.40(SD=0.81)
Caring Relationship	4.64(SD=0.61)
Agree on a measurable objective	4.37(SD=0.79)
Support goal achievement	4.31(SD=0.87)
Mean PM-CGS Factor Score[a]	4.47(SD=0.64)
Mean Self-Efficacy	5.80(SD=1.51)
Mean Trust in Physician	85.02(SD=14.14)
Self-Management	
General Diet	4.91(SD=1.74)
Specific Diet	4.22(SD=1.51)
Exercise	3.72(SD=2.23)
Blood Sugar Testing	5.04(SD=2.42)
Foot Care	4.17(SD=2.51)
Mean Self-Management Factor Score	4.37(SD=1.43)

[a] Cronbach's alpha=.927; Omega =.819

Figure 4.2 – Unadjusted Structure Equation Model Parameter Estimates

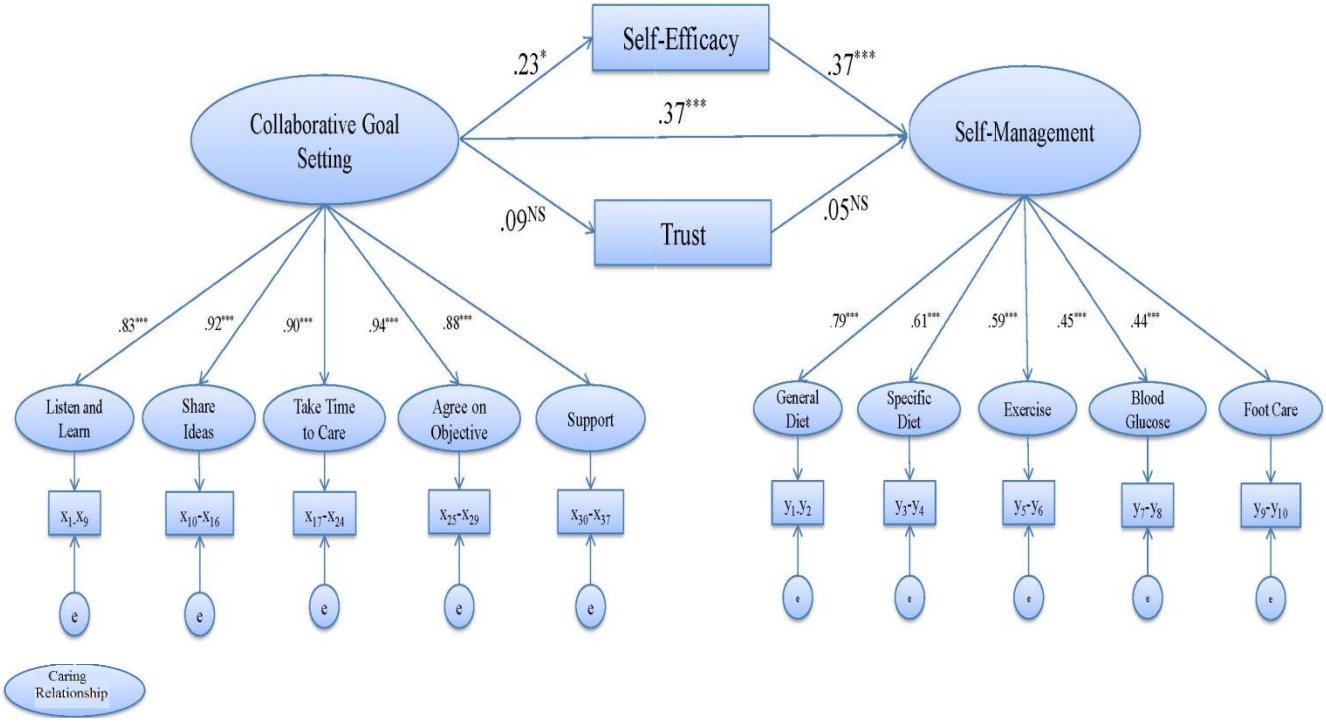


Table 4.3 – Adjusted Structural Equation Model Results Including Covariate Effects

	Collaborative Goal Setting	Self-Efficacy	Trust in Physician	Self-management
Socio-demographics				
Age	.06	.18**	.01	.00
Race				
Black	-.01	-.14	.14	.14
Other	.08	-.15*	-.12	.05
Education				
Less than HS	.12	.08	-.11	-.03
HS degree	-.03	-.11	-.09	-.20**

** p<.01

* p<.05

Chapter 5: Conclusions

Recent proposals have encouraged patients to become actively involved in the management of their health by being active participants in health care discussions.[11, 67] One method of doing so is by engaging in collaborative goal setting with their clinician. Individuals who have reported engaging in collaborative goal setting have been shown to have improvements in self-management and clinical control.[17, 18] The purpose of my dissertation research was to develop a patient-reported measure of collaborative goal setting. While the benefits of patient-reported engagement in collaborative goal setting had been previously identified, no previous studies examined this process from the patient's perspective. Therefore we knew little about how to monitor the use of collaborative goal setting in practice from the patient's perspective as well as how to foster this process in practice in order to improve health outcomes. Therefore, I first used qualitative research to explore patient perceptions of collaborative goal setting.

Findings from my research illustrated that collaborative goal setting from the patients' perspective is comprised of five domains: (1) listen and learn from each other, (2) share ideas, (3) a caring relationship, (4) agree on a measurable objective, and (5) support for goal achievement.[88] This conceptual framework was then used to guide the development of a measure of collaborative goal setting. My quantitative results illustrated both the construct[103] and the external validity[111] of this measure. Overall, findings put forth from my dissertation research provide a tool to measure the goal setting process to determine whether or not it was collaborative, while also enabling us to see what specific aspects of collaborative goal setting were present.

On the one hand, my findings are consistent with Heisler's prior conceptualization of collaborative goal setting[15] in that listen and learn, share ideas, and agree on a measureable

objective are important components of collaborative goal setting. These three domains closely resemble Heisler's concepts of patient and physicians: mutually agreeing upon the goal, the patient sharing beliefs about illness treatment and information about their life and values, and discussing self-care management options. The domains put forth by each of these conceptualizations are similar in that they necessitate the open exchange of information between patients and clinicians, where both individuals have a responsibility to be involved. As communication processes play such a pinnacle role in patient-provider care, it is of no surprise that these domains transcend multiple types of interactions. These communication processes are not exclusive to the realm of collaborative goal setting, but also extend to common definitions of shared decision-making,[19] as well as informed decision-making,[112] where this type of exchange of information is also necessary.[19, 112]

While the exchange of information between patients and clinicians is imperative to the collaborative goal setting process, my findings expand upon the understanding of collaborative goal setting by illustrating the importance of considering the context the goal setting conversation occurs in. Patients repeatedly emphasized that the communication surrounding goal setting needed to occur within the context of a caring relationship for it to be considered a collaborative process. This concept is in line with our previous understanding of the patient-provider relationship where the importance of the patient-centered relationship has been well established. The development and maintenance of a therapeutic relationship is one of the main functions of the medical interview and it directly impacts the quality of the information both elicited and understood by patients.[113] As such, the creation of a caring relationship between the patient and the clinician lays the foundation for the communication processes that transpire during clinical encounters and can directly affect their impact on goal achievement.

Another aspect of collaborative goal setting that needs to occur between patients and clinicians is the provision of support for goal achievement. While jointly establishing the goal with a clinician was viewed as important, it was equally important to have communication exchanges about how to make progress towards goal achievement. This is an important addition to the conceptualization of collaborative goal setting as it emphasizes the importance of extending goal setting conversations beyond the initial discussion where the goal was established. My findings support the need for information and strategies patients can take with them to use in order to make progress towards goal achievement. Ongoing support for goal achievement is consistent with that put forth within the Chronic Care Model where self-management support is a critical component of a practice's organization capacity.[11] Included within the Chronic Care Model is the use of action planning, a process that is closely related to goal setting, and is a process that is often advocated for.[114] Actions plans are a method of promoting goal achievement by providing a course of action for the patient to follow to make behavior changes and progress on their goal.[77] Not only do action plans give patients a direct plan to follow, but they are used with the purpose of increasing a patient's self-efficacy.[77] As goal setting and action plans are intertwined, it is not surprising that support for goal achievement [i.e. provision of strategies and information] is a concept of collaborative goal setting as described by patients.

Similar to the tool currently being used,[25] the PM-CGS allows researchers to determine whether or not a collaborative goal has been set from the patient's perspective. However, results from my dissertation research provide a new standard by which to determine whether or not a goal has been set collaboratively between a patient and the clinician. Not only does this tool enable us to assess whether a collaborative goal was set, but it also allows us to understand what

specifically occurred to cause patients to report engaging in collaborative goal setting. By doing so, we have the ability to understand the processes necessary to foster collaborative goal setting in practice.

Prior studies have shown improvements in health outcomes when collaborative goal setting was reported. Similar to these previous studies, my findings showed that when participants reported a collaborative goal had been set, they also noted that they had engaged in self-management behaviors more frequently. For my dissertation research, I utilized the 37-item PM-CGS that I developed to evaluate this relationship.[103] Consistent with previous findings, collaborative goal setting was found to have a positive, direct influence on self-management behaviors, as well as a positive impact on self-management mediated by a patient's self-efficacy. As such, further evidence has been provided regarding the benefits associated with patient reports of collaborative goal setting.

There is no standardized method, or gold standard, by which to engage in goal setting with patients. Results from my dissertation supplement the previous conceptualization of collaborative goal setting by providing an in-depth understanding of what patients state need to occur for a goal to be considered collaboratively set. Therefore, my findings serve as a foundation by which to help prevent, as well as control, chronic diseases like diabetes by providing a checklist of what needs to occur in order for clinical interactions about goal setting to be considered collaborative.

At the same time however, my findings also illustrate the challenges in doing so because for goal setting to be labeled collaborative it needs to occur across multiple visits and within a system of care that supports a caring relationship between the clinician and patient. In order to support a context where caring relationships occur as recommended by Epstein and Street,[67] and

provide the support necessary to engage in self-management behaviors outside the confines of the clinic as suggested by the Chronic Care Model,[11] system-wide changes would need to be made, which can take time and the necessary funds. Medical homes are an example of this type of system as they provide comprehensive care to patients with the use of a team based health care delivery system. In this type of system, not only does the medical care team provide self-management resources and use motivational interviewing, but patients are also contacted prior to the visit to discuss expectations.[115] Medical homes show potential for being a conducive environment for collaborative goal setting to take place in. However, challenges still remain.

The primary challenge to engaging patients in collaborative goal setting is time. Regardless of the health system, primary care discussions often contain multiple topics to be covered in a short visit, among which is goal setting. As such, it may be difficult to cover all points of conversation during a single visit while also hitting on all of the topics encompassed within a collaboratively set goal. Another challenge is that the visit may be set for a separate purpose and so goal setting may not be discussed to its full extent. Patients may set a visit to receive medical attention for an acute or chronic condition, and this may overshadow a patient that needs or wants to set a goal related to weight loss.

The manner in which collaborative goal setting is conducted, especially among patients with chronic illnesses, remains an omnipresent challenge. Further research is needed to determine not only how to foster a caring relationship within clinical encounters, but also how to foster communication processes across multiple visits. Future studies can use the results from my research to design communication skills training programs for clinicians and other interventions aimed at promoting collaborative goal setting between clinicians and their patients. Furthermore, this measure can be used to monitor for aspects of goal setting processes being used in practice

that are already consistent with what patients consider to be a part of a collaborative goal setting process.

My future research will focus on further testing of the PM-CGS to validate its efficacy. I am interested in creating interventions to help promote collaborative goal setting in practice that can then be assessed by the PM-CGS. As my interests stem beyond the realm of diabetes, I would like to adapt the measure to be used within other chronic illness populations to determine the benefits of this process. Because of my background in pediatrics, I would also like to adapt what I have learned through the development of my measure to understand the role and benefits of collaborative goal setting with pediatric patients. The dynamics that exist with parental involvement in addition to the patient-physician interaction would make this research area unique.

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Appendix A

A. Group Structure/Rules

The moderator will cover the items below.

- State his/her name
- Thank the participants for attending
- State that researchers are conducting a study to understand how doctors and patients set goals together
- State that participants will be asked to discuss their current treatment goals, how these goals were established, and what they think about goal setting
- Explain that researchers will summarize information provided and use the findings to help inform future work to develop and improve tools to help patients engage in goal setting with their doctors
- Explain that all findings from the session will be combined across all participants and that no names will be attached to comments
- Assure that all information provided will be kept in the strictest confidence and no information that identifies you will be shared with anyone
- Explain that there are no right or wrong answers but rather differing points of view. It is important that participants feel comfortable sharing their opinions when they differ from those of others
- Explain that there should be no direct or personal critiques of others responses
- Explain that participants do not need to answer questions that make them feel uncomfortable
- Explain that all information shared will be helpful and that it is important not to hold back opinions and ideas for fear that thoughts are boring or not important
- Encourage participants to speak loudly, but not interrupt others
- Explain that the moderator will try to get comments from everyone in the room, so if he/she hasn't heard from someone in a while, he may ask that person directly if they have something to say
- State that the session will be audio-recorded so as not to miss any comments; Encourage participants not to speak over each other as doing so garbles the recording
- Encourage participants to refer to each other by first name or preferred name given by the participant
- Explain that the session will last approximately 2 hours and that in the interest of time the moderator may have to interrupt and proceed to the next topic; Please don't take this to mean that we are not interested in what you are saying

B. Introduction/Ice Breaker

Before we begin our discussion, let's find out a little bit about each other. Let's go around the room, state your first name, or the name you want us to call you by, and tell us about your dream vacation. Please be sure to speak up so that we do not miss your voice on the tape.

C. Focus Group Probes

1. Experience with setting health-related goals.

The first thing we'd like to talk about is what type of health-related goals you have.

- When I use the word, “goal,” what does this mean to you?
- Currently, what kind of goals do you have for your health?
    - How did you pick this goal? Why did you select this goal?
- How do you involve others in setting your health-related goals?
    - Who typically helps you set your health-related goals?
- How often do you typically talk to other people (e.g. doctor, health care team, family, friends) when picking/making a health-related goal? When you do, how do you involve them?
    - Who do you talk to about your goals?
    - How do they help you set a goal?
        - How do those conversations go?
    - How do you take other people’s opinion into consideration when setting a goal?
- When you set a health-related goal, who should it be important to? Who gets to decide if the goal is important? Why?

2. Perception of collaborative goals.
We are interested in learning more about the different goal setting process you may use.

- When I say, “a goal was set collaboratively” between you and your health care provider, what does that mean to you?
- Some people prefer to set health-related goals collaboratively. In this situation, when a health-related goal is set, what do you think this conversation would sound like?
    - Who do you think would be involved in this process? A doctor? A member of the healthcare team?
    - What do you think has to happen for a goal to be collaboratively set?
        - What does the other individual need to do or say? What does the patient need to do or say?
- What does it mean when a healthcare team member and a patient agree upon a goal? How do you know when both people have agreed?
- There are things in your life that can affect the way you want to approach your diabetes treatment. This might be and event that is going on in your life, your values, or your beliefs. How do you share this information with your doctor or other members of your health care team? Why or why don’t you share this information?

- Is there anything that can be done to make it easier for you to share this type of information?

3. Patient perceptions of goal setting.
We would like to discuss goals that were set collaboratively and non-collaboratively.

- Have you ever set a collaborative goal about diabetes during a visit to your doctor or other health care provider?
    - How did you set this goal?
    - What was your part in setting this goal?
        - What about the doctor, or other health care provider? What role did they play?
    - What part of setting this goal made it a collaborative goal?
        - Was it the goal itself, or was it something that occurred between you and your doctor or other health care provider?
    - Is there anything you or anyone else could have done differently that would have made this a more satisfying interaction?
        - What about the physician or other healthcare provider? What could they have done?
- Have you ever had a goal for your health that was set during an office visit, but wasn't set collaboratively?
    - How was that goal set?
        - Who set the goal? What did they say?
    - What part of making this goal made it a non-collaborative goal?
        - Was it the goal itself, or was it something else that occurred?
- Can you think of anything anyone else could do to help you set goals regarding your diabetes care?
    - What about you healthcare provider or doctor? What could they do?
    - What are some examples of things already being done?

4. Patient-perceived informational needs

We are interested in hearing about the different types of information you feel it is important for patients to have when it comes to setting their health-related goals.

- What types of information might you want to have when setting a health-related goal?
    - What do you think are the best ways to get these types of information? How do you find this information?

- What information, if any, do you want to **get from** your doctor or other healthcare providers?

- What information, if any, do you want to **provide** to your doctor or other healthcare providers?

- Is there anything you can do to share more information with your doctor/healthcare provider?

- Is there anything you can do to get your doctor/healthcare provider to share more information with you?

    - What about the doctor/healthcare provider? What can he/she do to help you share more information? What help from your doctor do you need?

- Is there any information that could help you talk more easily with your healthcare provider/doctor about setting goals for your diabetes care?

5. Patient perceived emotional needs in goal setting.

The previous questions focused on information and how you get it. These next questions are aimed at focusing on emotional support and where you get this support from. Specifically, we'd like to hear your thoughts about how your emotional needs can be met when setting and achieving your health-related goals.

- Who do you go to for help setting goals?

    - How do you use your physician or other health care providers when setting your goals?

    - Are there things people can do to help you set health-related goals?

- How can you talk to your healthcare provider or doctor about your emotional needs when setting and then achieving goals?

    - Is there anything your healthcare provider or doctor can do to help you feel more comfortable sharing your emotional needs?

6. Patient preferences for goal setting.

We are interested in learning about your goal setting process.

- Some people like to work with their doctor/healthcare provider to set goals for their diabetes. Others want to make their own goals or have the doctor/healthcare provider set the goals for them. How do you like to set your goals for managing your diabetes? Why?

- What is important to you to do or say when you are collaborating with your doctor/healthcare provider to set a health-related goal?

- What problems do you think patients have when it comes to setting goals with healthcare providers/doctors?
    - What gets in the way of setting goals with healthcare providers/doctors?
    - What can your doctor/healthcare provider do to help you talk more easily with them? What about the patient; are there things they can do to make it more easy?

Ending / Conclusion of Focus Group

Okay, we've covered all the issues that I wanted to discuss. Before we finish, I want to give you the opportunity to reflect on our discussion and share anything that you think is relevant to goal-setting for patients with diabetes that didn't come up during the conversation.

Again, thank you very much for your honesty and willingness to participate in this group. We have learned a lot today, and your input will help us with developing a survey to improve care for patients with diabetes. If you'd like, please feel free to stay a bit if you have any questions about our research, or have any other comments you'd like to share.

Thanks again.

Appendix B

Health-Related Goal Setting Survey

Instructions

- You answers are strictly **private**.
- Please **do not** put your name on the survey.
- Answers from other people like you will be combined.
- Some questions are personal, but those questions provide important information for this study.
- It is **your** choice to skip any questions that you do not want to answer.
- Some questions may seem very similar, but please answer them all.
- The survey takes approximately 30-40 minutes to complete. **You will receive a $20 gift card to compensate you for your time and effort.**
- Please mark your answers as follows:

Answer selection: Correct = ☒ Incorrect = ☑

- Unless instructed otherwise, **mark only one answer** per item.
- You may use **pen or pencil** to complete this survey.

Thank you very much for taking the time to complete this survey! Your answers are important. When you are done, please mail it back in the enclosed stamped envelope.

1. Have you ever been told by a doctor or other health professional that you have diabetes, sugar diabetes, or high blood sugar?

- ☐ Yes. **Go to Question 2**
- ☐ Yes, but only during pregnancy.
- ☐ No.

You are not eligible for the survey. Please return the survey in the enclosed stamped envelope. Please keep the $2.00 bill as a token of our appreciation for your time.

2. What is your age? ___ ___ Years

3. Are you male or female?

- ☐ Male
- ☐ Female

4. In general, how would you rate your overall health?

- ☐ Excellent
- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor

5. What is your current marital status?

- ☐ Currently married & living together, or living with someone in marital-like relationship
- ☐ Never married
- ☐ Separated
- ☐ Divorced or formerly lived with someone in marital-like relationship
- ☐ Widowed

6. Which one or more of the following is your race? [Mark all that apply]

- ☐ White
- ☐ Black or African American
- ☐ Asian
- ☐ Native Hawaiian or other Pacific Islander
- ☐ American Indian or Alaska Native
- ☐ Other

7. What language do you usually speak at home?

- ☐ English
- ☐ Spanish
- ☐ Other (please specify): _____

8. Are you Hispanic or Latino?

- ☐ Yes
- ☐ No

9. What was the last year of school you completed?

- ☐ Never attended school or only attended kindergarten
- ☐ Grades 1 through 8 (Some or all Elementary)
- ☐ Grade 9 through 11 (Some high school)
- ☐ Grade 12 or GED (High school graduate)
- ☐ College 1 year to 3 years (Some college or technical school)
- ☐ College 4 years or more (College graduate)

Please tell us how true each of the following statements are for you with respect to dealing with your diabetes. (1=Not at all true; 7=Very True)

		1	2	3	4	5	6	7
10.	I feel confident in my ability to manage my diabetes	☐	☐	☐	☐	☐	☐	☐
11.	I am capable of handling my diabetes now	☐	☐	☐	☐	☐	☐	☐
12.	I am able to do my own routine diabetic care now.	☐	☐	☐	☐	☐	☐	☐
13.	I feel able to meet the challenge of controlling my diabetes	☐	☐	☐	☐	☐	☐	☐

14. Over the past 6 months, have you discussed a health-related goal with the doctor or other healthcare provider you see most often for your diabetes care? (Circle One)

☐ Yes

☐ No → **Skip to Question 71**

15. What type of healthcare provider did you speak to about the goal?

☐ Primary Care Doctor

☐ Endocrinologist

☐ Nurse Practitioner

☐ Nurse (RN or LPN)

☐ Other: _____

16. What was the primary topic of the health-related goal you discussed with your doctor or other healthcare provider:

- ☐ To lose weight
- ☐ To exercise more
- ☐ To control your blood pressure, lipid levels, or diabetes (A1c) better
- ☐ To eat healthier
- ☐ To stop smoking
- ☐ Other:_____

Thinking about that goal, how much do you agree or disagree with the following statements (1=Strongly Disagree; 5=Strongly Agree):

Listen and Learn from Each Other					
17. I asked my doctor any questions I had	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
18. My doctor explained the reasons for the goal	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
19. I learned important things from my doctor	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
20. My doctor asked me if I had any concerns	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
21. My doctor listened to what I had to say	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
22. My doctor and I discussed the reasons for the goal	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
23. I listened to what my doctor had to say	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
24. I told my doctor important things about me	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

		1	2	3	4	5
25.	My doctor explained things in a way that was easy to understand	☐	☐	☐	☐	☐
26.	I told my doctor about any concerns I had	☐	☐	☐	☐	☐
27.	My doctor gave me the opportunity to ask any questions I had	☐	☐	☐	☐	☐
Share Ideas						
28.	My doctor asked for my input	☐	☐	☐	☐	☐
29.	I told my doctor about important things in my life	☐	☐	☐	☐	☐
30.	My doctor shared his/her ideas with me	☐	☐	☐	☐	☐
31.	I made sure my doctor knew about things that were important to me	☐	☐	☐	☐	☐
32.	I was interested in my doctor's ideas	☐	☐	☐	☐	☐
33.	My doctor provided important medical information to me	☐	☐	☐	☐	☐
34.	I shared my ideas with my doctor	☐	☐	☐	☐	☐
35.	I felt confident my doctor understood what was important to me	☐	☐	☐	☐	☐
36.	My doctor seemed interested in my ideas	☐	☐	☐	☐	☐
Take Time to Care						

		1	2	3	4	5
37.	My doctor treated me as a person	☐	☐	☐	☐	☐
38.	My doctor was honest with me	☐	☐	☐	☐	☐
39.	I respected my doctor's opinions	☐	☐	☐	☐	☐
40.	My doctor showed he/she cared about me as a person	☐	☐	☐	☐	☐
41.	My doctor respected my opinion	☐	☐	☐	☐	☐
42.	My doctor spent enough time with me	☐	☐	☐	☐	☐
43.	I showed my doctor that I cared about achieving the goal	☐	☐	☐	☐	☐
44.	I was honest with my doctor	☐	☐	☐	☐	☐
45.	My doctor took time to understand what was important to me	☐	☐	☐	☐	☐
Articulate Measurable Objective						
46.	The goal set was achievable	☐	☐	☐	☐	☐
47.	My doctor helped me understand what the specific goal is	☐	☐	☐	☐	☐
48.	I had confidence that I could achieve the goal	☐	☐	☐	☐	☐
49.	My doctor and I agreed on the specific goal that was set	☐	☐	☐	☐	☐

		1	2	3	4	5
50.	I felt good about the goal	☐	☐	☐	☐	☐
51.	My doctor and I discussed the potential specifics of the goal	☐	☐	☐	☐	☐
Support Goal Achievement						
52.	My doctor gave me information I could take home about the goal	☐	☐	☐	☐	☐
53.	I was comfortable discussing any challenges I might have achieving the goal	☐	☐	☐	☐	☐
54.	I told my doctor I felt like I could achieve the goal	☐	☐	☐	☐	☐
55.	My doctor and I discussed strategies for achieving the goal	☐	☐	☐	☐	☐
56.	I was confident I knew how to achieve the goal	☐	☐	☐	☐	☐
57.	My doctor made me feel like I could achieve the goal	☐	☐	☐	☐	☐
58.	My doctor described how to achieve the goal	☐	☐	☐	☐	☐
59.	My doctor and I came up with a strategy for how to achieve the goal	☐	☐	☐	☐	☐
60.	My doctor checked to make sure I understood the goal	☐	☐	☐	☐	☐

61. Have you met with your doctor since the goal was set?

☐ Yes – **Keep Going**

☐ No – **Skip to Question 71**

62.	I have followed up with my doctor about the goal	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
63.	My doctor and I have talked about any progress made toward the goal	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
64.	My doctor has checked in to see how I was doing with the goal	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
65.	My doctor has followed up with me about the goal	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
66.	My doctor and I have celebrated the progress I have made towards the goal	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
67.	My doctor has encouraged me to keep trying	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

68. Have you achieved your goal?

☐ Yes

☐ No

69. Are you making progress towards the goal?

☐ Yes

☐ No

70. How much progress?

☐ A lot

☐ A little

☐ None

The questions below ask you about your diabetes self-care activities during the past 7 days. If you were sick during the past 7 days, please think back to the last 7 days that you were not sick.

71.	How many of the last SEVEN DAYS have you followed a healthful eating plan?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
72.	On average, over the past month, how many DAYS PER WEEK have you followed your eating plan?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
73.	On how many of the last SEVEN DAYS did you eat five or more servings of fruits and vegetables?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
74.	On how many of the last SEVEN DAYS did you eat high fat foods such as red meat or full-fat dairy products?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
75.	On how many of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, including walking).	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
76.	On how many of the last SEVEN DAYS did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or as part of your work?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
77.	On how many of the last SEVEN DAYS did you test your blood sugar?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
78.	On how many of the last SEVEN DAYS did you test your blood sugar the number of times recommended by your health care provider?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
79.	On how many of the last SEVEN DAYS did you check your feet?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
80.	On how many of the last SEVEN DAYS did you inspect the inside of your shoes?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐

81.	Have you smoked a cigarette – even one puff – during the past SEVEN DAYS?	Yes ☐	No ☐	*If* **yes,** how many cigarettes did you smoke on an average day?	_____

The next questions are focused on understanding your knowledge of diabetes.

82. The diabetes diet is:

- ☐ The way most American people eat
- ☐ A healthy diet for most people
- ☐ Too high in carbohydrate for most people
- ☐ Too high in protein for most people

83. Which of the following is highest in carbohydrate?

- ☐ Baked chicken
- ☐ Swiss cheese
- ☐ Baked potato
- ☐ Peanut Butter

84. Which of the following is highest in fat:

- ☐ Low fat milk
- ☐ Orange juice
- ☐ Corn
- ☐ Honey

85. Which of the following is a "free food":

- ☐ Any unsweetened food
- ☐ Any dietetic food
- ☐ Any food that says "sugar free" on the label
- ☐ Any food that has less than 20 calories per serving

86. Glycosylated hemoglobin (hemoglobin A1) is a test that is a measure of your average blood glucose level for the past:

- ☐ Day
- ☐ Week
- ☐ 6-10 weeks
- ☐ 6 months

87. Which is the best method for testing blood glucose?

- ☐ Urine testing
- ☐ Blood testing
- ☐ Both are equally good

88. What effect does unsweetened fruit juice have on blood glucose?

- ☐ Lowers it
- ☐ Raises it
- ☐ Has no effect

89. Which should not be used to treat low blood glucose?:

- ☐ 3 hard candies
- ☐ ½ cup orange juice
- ☐ 1 cup diet soft drink
- ☐ 1 cup skim milk

90. For a person in good control, what effect does exercise have on blood glucose:

- ☐ Lowers it
- ☐ Raises it
- ☐ Has no effect

91. Infection is likely to cause:

- ☐ An increase in blood glucose
- ☐ A decrease in blood glucose
- ☐ No change in blood glucose

92. The best way to take care of your feet is to:

- ☐ Look at and wash them each day
- ☐ Massage them with alcohol each day
- ☐ Soak them for one hour each day
- ☐ Buy shoes a size larger than usual

93. Eating foods lower in fat decreases your risk for:

- ☐ Nerve disease
- ☐ Kidney disease
- ☐ Heart disease
- ☐ Eye disease

94. Numbness and tingling may be symptoms of:

- ☐ Kidney disease
- ☐ Nerve disease
- ☐ Eye disease
- ☐ Liver disease

95. Which of the following is usually not associated with diabetes:

- ☐ Vision problems
- ☐ Kidney problems
- ☐ Nerve problems
- ☐ Lung problems

96. Signs of ketoacidosis include:

- ☐ Shakiness
- ☐ Sweating
- ☐ Vomiting
- ☐ Low blood glucose

97. If you are sick with the flu, which of the following changes should you make?

- ☐ Take less insulin
- ☐ Drink less liquids
- ☐ Eat more proteins
- ☐ Test for glucose and ketones more often

98. If you have taken intermediate-acting insulin (NPH or Lente), you are most likely to have an insulin reaction in:

- ☐ 1-3 h
- ☐ 6-12 h
- ☐ 12-15 h
- ☐ More than 15 h

99. You realize just before lunch time that you forgot to take your insulin before breakfast. What should you do now?

- ☐ Skip lunch to lower your blood glucose
- ☐ Take the insulin that you usually take at breakfast
- ☐ Take twice as much insulin as you usually take at breakfast
- ☐ Check your blood glucose level to decide how much insulin to take

100. If you are beginning to have an insulin reaction, you should:

- ☐ Exercise
- ☐ Lie down and rest
- ☐ Drink some juice
- ☐ Take regular insulin

101. Low blood glucose may be caused by:

- ☐ Too much insulin
- ☐ Too little insulin
- ☐ Too much food
- ☐ Too little exercise

102. If you take your morning insulin but skip breakfast your blood glucose level will usually:

- ☐ Increase
- ☐ Decrease
- ☐ Remain the same

103. High blood glucose may be caused by:

- ☐ Not enough insulin
- ☐ Skipping meals
- ☐ Delaying your snack
- ☐ Large ketones in your urine

104. Which of the following will most likely cause an insulin reaction:

- ☐ Heavy exercise
- ☐ Infection
- ☐ Overeating
- ☐ Not taking your insulin

Thinking about your doctor or other health care professional, how much do you agree or disagree with the following statements (1=Strongly Disagree, 5=Strongly Agree):

		1	2	3	4	5
105.	I doubt that my doctor really cares about me as a person.	☐	☐	☐	☐	☐
106.	My doctor is usually considerate of my needs and puts them first	☐	☐	☐	☐	☐
107.	I trust my doctor so much I always try to follow his/her advice.	☐	☐	☐	☐	☐
108.	If my doctor tells me something is so, then it must be true.	☐	☐	☐	☐	☐
109.	I sometimes distrust my doctor's opinions and would like a second one.	☐	☐	☐	☐	☐
110.	I trust my doctor's judgments about my medical care.	☐	☐	☐	☐	☐
111.	I feel my doctor does not do everything he/she should about my medical care.	☐	☐	☐	☐	☐
112.	I trust my doctor to put my medical needs above all other considerations	☐	☐	☐	☐	☐

	when treating my medical problems.					
113.	My doctor is a real expert in taking care of medical problems like mine.	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
114.	I trust my doctor to tell me if a mistake was made about my treatment.	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
115.	I sometimes worry that my doctor may not keep the information we discuss totally private.	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

116. On average, about how many days per week do you engage in moderately strenuous or strenuous activities requiring at least as much effort as the following examples: climbing up or down stairs, walking fast, using a lawnmower, sawing wood, bicycling, dancing, or playing tennis?

0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ days

117. On the days when you do engage in moderately strenuous or strenuous activities, how many minutes do you spend on average per day doing that activity?

- ☐ Less than 30 minutes a day
- ☐ Between 30-60 minutes a day
- ☐ Between 60-90 minutes a day
- ☐ More than 90 minutes a day

118. Have you smoked at least 100 cigarettes in your ENTIRE LIFE?

- ☐ Yes
- ☐ No
- ☐ Don’t know/Not sure

119. Do you NOW smoke cigarettes every day, some days, or not at all?

- ☐ Every day
- ☐ Some days
- ☐ Not at all
- ☐ Don’t know / Not sure

120. On average, how many days per week do you drink alcohol?

0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ days

121. On a typical day when you drink, how many drinks do you have? ___ ___

122. Over the past two weeks, how often have you been bothered by feeling down, depressed or hopeless?

- ☐ Not at all
- ☐ Several days
- ☐ More than half the days
- ☐ Nearly every day
- ☐ Don’t know

123. Over the last two weeks, how often have you been bothered by little interest or pleasure in doing things?

- ☐ Not at all
- ☐ Several days
- ☐ More than half the days
- ☐ Nearly every day
- ☐ Don’t know

124. How many people live with you?

0	1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

125. Are you currently working for pay or profit?

☐ Yes → **If Yes,** how many hours per week? _____

☐ No

126. Are you CURENTLY covered by any of the following types of health insurance or health coverage plans?		
Mark Yes or No for Each type of coverage in items a – h.	**Yes**	**No**
a. Insurance through a current or former employer or union (by you or another family member)	☐	☐
b. Insurance purchased directly from an insurance company (by you or another family member)	☐	☐
c. Medicare, for people 65 and older, or people with certain disabilities	☐	☐
d. Medicaid, Medical Assistance, or any kind of government-assistance plan for those with low incomes or a disability	☐	☐
e. TRICARE or other military healthcare	☐	☐
f. VA (including those who have ever used or enrolled for VA healthcare)	☐	☐
g. Indian Health Service	☐	☐
h. Any other type of health insurance or health coverage plan (specify): _____	☐	☐

127. Thinking about members of your family living in this household, what is your combined annual income, meaning the total pre-tax income from all sources earned in the past year?

- ☐ $0 to $9,999
- ☐ $10,000 to $14,999
- ☐ $15,000 to $19,999
- ☐ $20,000 to $34,999
- ☐ $35,000 to $49,999
- ☐ $50,000 to $74,999
- ☐ $75,000 to $99,999
- ☐ $100,000 to $199,999
- ☐ $200,000 or more

128. What kind of gift card would you like? Mark only one:

- ☐ Food Lion
- ☐ Walmart

Thank you very much for completing your survey.
<<Insert ID>>
Please place it in the enclosed, stamped envelope and drop it in the mail for us!

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Vita

Heather Lynne Morris was born February 10, 1986 in Kewanee, Illinois and is an American citizen. She graduated Magna Cum Laude with her Bachelor of Arts in Human Development and Family Resources with a minor in Spanish from Illinois State University in Normal, Illinois in 2007. She received her Master of Science in Child Life from Illinois State University in Normal, Illinois in 2009 and is a Certified Child Life Specialist. Before beginning her doctoral studies at Virginia Commonwealth University, Heather worked as a child life specialist in the Pediatric Intensive Care Unit. Working with patients and their families was what motivated her to receive her doctoral degree focused on improving doctor patient communication. While at Virginia Commonwealth University, Heather received an R36 Dissertation Award from the Agency for Healthcare Research & Quality (R36 HS022202-01).