IMPROVING PEDIATRIC TYPE-1 DIABETES MELLITUS MANAGEMENT IN
RURAL UTAH: A CASE STUDY

by

Sean Lucien Olsen

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GRADUATE COLLEGE

As members of the DNP Project Committee, we certify that we have read the DNP Project prepared by Sean Lucien Olsen entitled Improving Pediatric Type-1 Diabetes Mellitus Management in Rural Utah: A Case Study and recommend that it be accepted as fulfilling the DNP Project requirement for the Degree of Doctor of Nursing Practice.

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Final approval and acceptance of this DNP Project is contingent upon the candidate’s submission of the final copies of the DNP Project to the Graduate College.

I hereby certify that I have read this DNP Project prepared under my direction and recommend that it be accepted as fulfilling the DNP Project requirement.

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STATEMENT BY AUTHOR

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SIGNED: Sean Lucien Olsen
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To my grandparents Boyd Paul & Marilyn Smith Anderson. Without your continued support and encouragement throughout my life, my accomplishments would be few.

To my family, for putting up with me during the last decade for the countless times I told you, “I can’t. I have to do school”.

To my little girl Adalee, for the innumerable hours you spent at the desk sitting on my lap being my favorite study partner.

To my wife, Sallie. Your support throughout these few years is appreciated more than you know. Thank you for being willing to help in any way while I pursued my goals.
DEDICATION

Can't is the worst word that's written or spoken;
Doing more harm here than slander and lies;
On it is many a strong spirit broken,
And with it many a good purpose dies.
It springs from the lips of the thoughtless each morning
And robs us of courage we need through the day:
It rings in our ears like a timely sent warning
And laughs when we falter and fall by the way.

Can't is the father of feeble endeavor,
The parent of terror and halfhearted work;
It weakens the efforts of artisans clever,
And makes of the toiler an indolent shirk.
It poisons the soul of the man with a vision,
   It stifles in infancy many a plan;
   It greets honest toiling with open derision
And mocks at the hopes and the dreams of a man.

Can't is a word none should speak without blushing;
   To utter it should be a symbol of shame;
   Ambition and courage it daily is crushing;
It blights a man's purpose and shortens his aim.
Despise it with all of your hatred of error;
Refuse it the lodgment it seeks in your brain;
Arm against it as a creature of terror,
And all that you dream of you someday shall gain.

Can't is the word that is for to ambition,
An enemy ambushed to shatter your will;
Its prey is forever the man with a mission
And bows but to courage and patience and skill.
Hate it, with hatred that's deep and undying,
For once it is welcomed 'twill break any man;
Whatever the goal you are seeking, keep trying
and answer this demon by saying: "I can."

- Edgar A. Guest
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ABSTRACT

Introduction: Poor glycemic control has been shown to exert deleterious influences on multiple body systems. Additionally, residing in a rural area is associated with poorer diabetes care. The rural adolescent patient described in this case study has a well-documented history of poor T1DM control. Her pediatric endocrinologist is located over two hours away from her home. Reported blood glucose levels average above 200 mg/dL, with a recent glycosylated hemoglobin (HbA1c) level of 10.3%. Previous blood glucose levels have reached an excess of 900 mg/dL. This study attempts to identify the beliefs of a rural T1DM adolescent patient, her mother, and her pediatric endocrinologist as they pertain to the patient’s T1DM management.

Methods: An embedded single case design with multiple embedded units of analysis was applied. Data was collected from the patient, mother, and pediatric endocrinologist between May and June of 2016. The design consisted of a mixed method approach that collected data using the Patient, Parent, and Provider Perception Questionnaire (P4Q). A triangulation of the responses from these subjects was used to elicit differences and similarities of disease management perceptions.

Results: There is disconnect in diabetes care management noted in most aspects of the patient’s treatment program.

Interpretation: Disconnect can occur in the management of rural adolescent diabetes. Understanding theoretical propositions of the HPM may provide a pathway to limiting the shortfalls in patient care, which may lead to improvement in rural adolescent diabetes outcomes.
INTRODUCTION

Background Knowledge

Type 1 Diabetes Mellitus (T1DM) is a chronic disease that is caused by the insufficiency of insulin subsequent to the destruction of the insulin-producing pancreatic beta cells (Levitsky & Misra, 2014). During 2008-2009, approximately 18,436 people under the age of 20 were diagnosed with T1DM in the United States, with most incidences affecting non-Hispanic white populations (Centers for Disease Control and Prevention [CDC], 2014). The Utah Public Data Health Resource (2015) indicates that during 2008, Utah experienced a diabetes incidence rate of 3 per 1,000 children under the age of 18, with the majority of diagnoses being T1DM. The majority of these are cases of T1DM.

In addition to psychological ailments such as depression and eating disorders, the deleterious effects of poor glycemic control (hyperglycemia) lead to vascular and neurologic diseases including neuropathy, retinopathy, and nephropathy (Levitsky & Misra, 2015). It has been found that even though complications typically occur later in life, pathogenesis of morbidities begin at disease onset. Despite the burden diabetes exerts on adolescents as they navigate through developmental stages, adequate glucose control is essential. Unfortunately for adolescents between age 11 and 15, diabetes management can be challenging given their cognitive maturity. This present-oriented age group is susceptible to feelings of self-consciousness, while facing hormonal fluctuations, bouts of rebellion, and strong peer relationships (Schreiner, Brow, Phillips, 2000). Additionally, physiologic variations that arise during this time encourage insulin resistance, making optimal control arduous (Schreiner, Brow, Phillips, 2000).
Under ideal conditions, meeting the American Diabetes Association (ADA) recommendations for diabetes care can be trying for young adolescents. These challenges are prominent in rural populations due to the relative nonexistence of local accessible diabetes care infrastructure (e.g., specialists, funding). Previous studies performed in rural populations have found that difficulties in meeting ADA recommendations include elements that are specific to regional areas, and are not able to be generalized nationally (Hale, Bennett, Probst, 2010).

Clinical practice guidelines suggest that children suspected to have T1DM be referred on the same day to a multidisciplinary pediatric diabetes management team (National Collaborating Centre for Women’s and Children’s Health [NCC-WCH], 2015). The ADA recommends that diabetic patients with T1DM incorporate providers with proficiency in T1DM management, such as an endocrinologist, diabetes educators, dieticians, exercise specialists, and mental health professionals (Chiang, Kirkman, Laffel, Peters, 2014). Guidelines also recommend and support the pediatric patient attend the diabetes clinic a minimum of every 3 months, and for those over the age of 12 to be monitored and evaluated for hypertension, microalbuminuria, and thyroid disease (NCC-WCH, 2015).

Poor access to providers has been acknowledged as a central barrier to obtaining optimal diabetes outcomes (Jones, Crabb, Turnbull, Oxlad, 2014), resulting in rural communities experiencing a lower quality of diabetes care than urban counterparts (Toledo, Triola, Ruppert, Siminerio, 2012). Therefore, patients who fail to access multidisciplinary services anticipate their local primary care provider will fulfill multiple roles within a limited amount of visits and may not appreciate the significance of the roles of other health practitioners in their diabetes cares (Madden, Barnard, Owen, 2013).
Barriers to care inhibit the rural patient and parent’s ability to access, receive, and utilize quality, comprehensive care, leading to significant burdens including the early onset of diabetes related health disparities. Thus, it is crucial that the presence of barriers of disease management be identified and addressed immediately to improve the quality of care and the patient’s disease outcomes (Valenzuela et al., 2014).

**Local Problem**

Patients who reside in rural areas face barriers to health care that can exacerbate health disparities (Tonks et al., 2012). This includes both geographical and financial difficulties. The geographical location of the patient presents as one of the greatest challenges in obtaining sufficient care (Thomas, DiClemente, & Snell, 2012). Remote locations of rural communities and the subsequent sparse population make it difficult to sustain specialist providers. Thus, the primary care provider is often required to apply their broad knowledge base in managing complex disease processes. Financially, patients and their families can face financial barriers when the cost of vehicle operation, gasoline, lost wages, dining expenses and medical co-pays are factored in.

This study focuses on an adolescent in rural Utah who has poorly controlled type-1 diabetes (T1DM) and a history of emergent transports via helicopter for related complications. The majority of Utah land area is considered to be rural, as 80% of the state’s population resides along the urban Wasatch Front (Western Rural Development Center, 2011). The closest facility accessible to the subject is a 25-bed critical access hospital (CAH) with six family practice providers and limited services. In order to attend her pediatric endocrinologist at Primary Children’s Hospital, the patient and her family must navigate over 260 miles round trip of roads
that traverse mountain passes, canyons, and valleys, all of which are vulnerable to severe inclement weather.

**Purpose of Study**

The purpose of this case study is to use Pender’s HPM to compare beliefs, barriers, and challenges regarding management for T1DM between a rural 13-year-old female with poorly controlled T1DM, her mother, and her remote diabetes specialist located 2 hours away in Salt Lake City. The goal is to better understand the beliefs of barriers to obtaining improved glycemic outcomes.

**Guiding Framework**

The Pender Health Promotion Model (HPM) (Figure 1) assists health providers to identify and articulate the motives behind patient health behaviors as they relate to disease management expectations (Pender, 2011; Ho, Berggren, Dahlbord-Lykhage, 2010). The HPM focuses on one’s characteristics, experiences, health behavior cognition, and behavioral results. Six variables that can be altered with nursing intervention serve as the basis of the model. They include:

- Conceptualized benefits of action
- Conceptualized barriers to action
- Circumstantial influences
- Social influences
- Assumed self-efficacy
- Activity related affects

(Ho, Berggren, Dahlborg-Lyckhage, 2010)
FIGURE 1. Pender’s Health Promotion Model (Pender, 2011).

The model is philosophically and theoretically rooted in the idea that people will interact with their environment until their needs are met or goals have been achieved (Pender, 2011). The HPM suggests that in order for people to change their health behaviors, their perceptions must first be addressed (Pender, 2011).

Pender’s model is a benefit to this study because it underlines the importance of health provider recognition and action toward modifiable behavioral beliefs that apply to rural pediatric T1DM patients, so that favorable disease outcomes are achieved.
**Intended Improvement**

The improvement anticipated by this case study include evaluating barriers perceived by the young patient, her mother, and the endocrinologist in regard to improving the patient’s diabetes care. Due to the excessive number of deleterious hyperglycemic episodes this patient has experienced, it is vital that an understanding of expectations between those involved is established hereupon to prevent acute and chronic morbidity.

Advanced Practice Registered Nurses (APRN), primary care providers, and other diabetes providers will be able to use these findings to gain insight in improving pediatric diabetes care in rural settings through understanding what the rural patient and their parents perceive as significant in diabetes management. Additionally, the aforementioned providers will be able to utilize the findings to address barriers that may occur while managing diabetes care in this population.

**Patient Information**

The patient subject is a 13-year-old female with uncontrolled T1DM despite using continuous subcutaneous insulin infusion pump therapy. Diagnosed in October of 2011, her current reported home glucose averages read in excess of 200 mg/dL, resulting in her last glycosylated hemoglobin (HbA1c) level of 10.3%. She has been hospitalized over 10 times for hyperglycemia or diabetic ketoacidosis (DKA) since being diagnosed, and has initiated even more emergency room visits. Recently, this patient required emergent air ambulance transportation to Primary Children’s Hospital in Salt Lake City for a blood glucose level of 981 mg/dL. Given her distant location and consequent poor access to specialized diabetes care, she is
required to travel over two hours each direction to the remote specialist in Salt Lake City for
disease management during scheduled endocrinology appointments.

Study Question

What are the challenges and barriers to adolescent diabetes management and glycemic
control as believed by a rural T1DM patient, her mother, and her remote pediatric
endocrinologist?

METHODS

Theoretical Framework

A case study approach will be employed to collect, analyze, and report findings, to
develop a deeper understanding into the patient’s poor T1DM outcomes. An embedded single-
case design was used for this quality improvement project given that the differences and
similarities of beliefs may provide insight into how her diabetes management can improve.
Beliefs were defined as the recognition and interpretation of information to understand the
patient’s goals, treatment plans, risks, and long-term effects of poor glycemic control. Control
was defined as an absence of hypoglycemic/hyperglycemic events with an HbA1c ≤ 6.5% (NCC-
WCH, 2015). Additionally, control was defined as a preprandial blood glucose range of 90-130
mg/dL, a postprandial blood glucose range of 120-180 mg/dL, and a bedtime blood glucose
range of 90-150 mg/dL (ADA, 2015). The design was imbedded within the same context, rural
pediatric management of a type-1 diabetic, as seen in Figure 2. The beliefs of the patient, her
mother, and her endocrinologist were assessed as they relate to the effect her rural location exerts
on her T1DM diagnosis.
The Plan, Do, Study, Act (PDSA) Quality Improvement cycle (Institute for Healthcare Improvement [IHI], 2016) was implemented to define the subsequent stages with interpretation and integration of the outcomes from this case study. The Plan phase of the PDSA cycle included defining the objective of identifying the beliefs of the above-mentioned subjects regarding the patient’s T1DM. The Do contained collection of responses through the P4Q to distinguish views. The Study phase included a triangulation analysis of the embedded case study using Pender’s Health Model as a framework. The Act phase could incorporate communicating the findings toward the subjects involved, as well as disseminating information to those managing pediatric T1DM in rural Utah. Should the information collected not have revealed assorted perceptions, the study approach could have been altered or further refined (US Department of Health and Human Services [USDHHS, 2011]).
Methods of Evaluation

Pender developed her questionnaire using components of the health promotion model. Patient characteristics and experiences are assessed, to which she expands questions based on the patient’s prior related behavior, personality structure, age, commitment, and socioeconomic status. Furthermore, her questions are established to help the patient distinguish his or her perceptions of barriers, benefits, and feelings as they relate to organizing and accomplishing the new task, and addressing the perceptions of the patient’s social support (Pender, 2011).

For this study, the tenets of the questions developed and published by Pender remain intact after manipulations within the P4Q were made to address the patient’s personal disease, experiences, and characteristics (Wu, Ronis, Pender, & Jwo, 2002). Additionally, Pender’s questionnaire underwent similar adaptations to obtain parallel information from her mother and the diabetes specialist, so that a triangulation of their beliefs could occur. To further ensure validity of the P4Q, an unbiased diabetes expert assessed the questionnaire and deemed it acceptable for use.

In order to obtain robust findings, consistency within the results from the P4Q completed by the three participants was triangulated. Validity of the results was increased through the method of triangulation itself, as it is described as a technique where investigators examine convergence amid various reliable sources of information (Golafshani, 2003). Credibility is also enriched through using multiple sources of information and collecting results from several perspectives. Quality of the data is enhanced by the conjunction and confirmation of findings (Baxter & Jack, 2008).
Project Design

This project is a single case study with multiple embedded units of analysis. It will utilize triangulation as an analysis of the responses made to the P4Q by each participant to assess beliefs and perceptions of background factors (e.g., biological, psychological, socio-economical factors; prior behaviors), as well as explore the similarities and differences that may influence the patient’s T1DM outcomes (Baxter & Jack, 2008).

Setting

The patient and her mother reside in a rural Utah agriculture and mining community approximately 125-175 miles from Salt Lake City. The patient’s primary care provider and emergency service access point are both located in this town. The local hospital is a 25-bed critical access facility. Her endocrinologist is located within Primary Children’s Specialty Hospital in Salt Lake City which is over two hours away in each direction. Consequently, the patient’s location, she does not have immediate physical access to additional diabetes resources (e.g., registered dietitian, support groups, etc.).

Data Collection

The design consists of a qualitative approach that systematically collected information using the P4Q. This data was collected from the patient, her mother, and endocrinologist between May and June 2016, using the P4Q questionnaire displayed in Appendix A. The P4Q was developed using Pender’s HPM and is adapted from the Clinical Assessment for Health Promotion Plan (Pender, 2011). The P4Q was delivered in an electronic format to each participant’s given email address from the Investigators University of Arizona email account. Each participant then completed the P4Q. The questionnaire offered unlimited space for
participants to provide a detailed answer to the open-ended questions. The email contained a disclosure notice tailored to each participant outlining the study, and notifying the subject that participation was completely voluntary. The email also asked the participants to be as descriptive as possible while answering the questions, as well as completing the questionnaire privately. A link to the survey was located at the bottom of the page which when clicked, confirmed the subject willingness to participate and have their responses used for research purposes. Once the link was clicked, it redirected the subject to the Qualtrics Platform website. Qualtrics is a secure web based research software that assists researchers with data collection and analysis. If necessary, email correspondence for follow up would have occurred to clarify any uncertainties and record additional comments from the participants. The completed P4Q was saved using the Qualtrics program that allowed the investigator to transfer the information to a table created in Microsoft Excel.

**Ethical Considerations**

Given the number of participants, the University of Arizona Human Protection Program deemed that this study did not qualify as human subject research. However, since the patient is under the age of 18, she is considered to be a member of a vulnerable population. Because of the patient’s age, her mother as her legal guardian provided informed consent. The informed assent of the patient was also obtained; after ensuring that information related to the investigation had been explained in terms she fully understood. Regardless of the patient’s ability to formulate a decision, it was assumed that her age her practical reasoning may not be fully developed and may deviate from mature judgment. It was also possible that as a result of her age she may fail to fully understand the complexities of situations that may have occurred (Rhodes, 2010).
Respect for Persons

According to the Belmont Report, respect for persons helps ensure that autonomy and protections are maintained for the patient. This will be addressed by not influencing her using the investigators personal opinions and choices (Yale, 2006). Regardless of needs deemed necessary for this study, she shall remain free to function and manage her T1DM as she pleases.

Beneficence

Beneficence will require that efforts be made to secure the well being of the patient subject, by respecting her decisions and protecting her from harm (Yale, 2006). By way of identifying the barriers and challenges encountered between the patient, her mother, and her diabetes specialist, a focus of the study will be to maximize health benefits, and minimize risk of harm. To help achieve beneficence in the study, the risks associated with participation will be discussed with the patient and her mother.

Justice

Because the case study only involves the patient, her mother, and the endocrinologist, I do not anticipate encountering scarcity or competition of benefits. Due to the focus on only one individual’s care, the study lacks the number of subjects that would necessitate equal distribution of benefits.

Trustworthiness

Triangulation will promote trustworthiness and credibility of the findings by ensuring robust and comprehensive participant accounts. The in-depth findings also boost the level of trustworthiness through transferability, seeing how other health care providers who oversee the diabetes care of rural adolescents can apply the information contained within the study to their
practice. Even though the report highlights the uniqueness of a single adolescent, it is anticipated that the results can be repeated in situations with similar variables. Lastly, the investigator maintained neutrality by allowing the participants to complete the P4Q individually in private. The investigator does not have the prospect of personal gain from the outcome of the study, further increasing the trustworthiness of the investigation (Cohen & Crabtree, 2006).

**Data Analysis**

This quality improvement project used a word table format that systematically organized the responses to the P4Q by the respondent and specific question (Miles & Huberman, 1994). Key patterns of time, events that occurred, as well as types of event words were evaluated for each response. The resulting table of patterns was then examined for descriptive patterns and causal relationships. The resulting word table analysis was delivered to content experts for agreement.

The content experts employed single word analysis that originates with identifying the research question and evaluating samples. Once the reviewer autonomously decided their own word samples, the words were coded into content categories. This in a sense is a method of selective reduction that reduced the participant responses down to a single word or short set of words that the reviewer was able to identify and code for. These words were able to help detect certain patterns that are indicative of the study inquiry.

The reviewers were given guidelines for analysis that included:

- Use single word analysis
- Chose a word that is most relevant to the question being asked
- Code for the existence of the concept, rather than the frequency
• There can be some generalization in distinguishing among concepts, since the participants will have different literacy levels

• Keep notes about decisions being made for generalizing words so that decisions are consistent

• Scan the answers and list the name of the chosen concept in the column

• So long as two of the three reviewers link a common theme from the content, that theme will serve as the agreed upon concept

**Dissemination**

It is anticipated that the information garnered from this study shall be of benefit to the participants as well as health care providers in similar situations. Therefore, a tailored communication strategy could be used to disseminate findings (Agency for Healthcare Research and Quality [AHRQ], 2012). Tailored communication aims to enhance the relevance of findings to produce greater desired change responses. Information regarding the subject is used to establish what content the participants and providers will receive, the context of the content, who shall present the content, and through which means the content will be conveyed (Hawkins, Kreuter, Resnicow, Fishbein, Dijkstra, 2007). An electronic executive summary that highlights findings and recommendations based upon evidence-based practices can be made available.

**RESULTS**

Between March and June 2016, all three of the participants responded to the P4Q (Appendix A) in full. The information was then provided electronically to three content reviewers who analyzed the information to code for specific themes found in Table 1. Themes were similar but used different descriptive words. For example, in Question #3 the reviewers
identified the themes of quality of life, well being and feeling good. It is observed based upon the
coded differences between responses that disengagement between the patient, her mother, and
the endocrinologist exists.


<table>
<thead>
<tr>
<th>Question #1</th>
<th>Question #2</th>
<th>Question #3</th>
<th>Question #4</th>
<th>Question #5</th>
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</thead>
<tbody>
<tr>
<td>Reviewer #1</td>
<td>Insulin</td>
<td>Adherence</td>
<td>Quality of Life</td>
<td>Acceptance</td>
</tr>
<tr>
<td>Reviewer #2</td>
<td>Insulin</td>
<td>Perseverance</td>
<td>Well-being</td>
<td>Disappointment</td>
</tr>
<tr>
<td>Reviewer #3</td>
<td>Management</td>
<td>Success</td>
<td>Feeling Good</td>
<td>Frustration</td>
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</table>

<table>
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<tr>
<th>Question #6</th>
<th>Question #7</th>
<th>Question #8</th>
<th>Question #9</th>
<th>Question #10</th>
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<tbody>
<tr>
<td>Reviewer #1</td>
<td>Skills</td>
<td>Mother’s Role</td>
<td>Responsibility</td>
<td>Pressure</td>
</tr>
<tr>
<td>Reviewer #2</td>
<td>Proficient</td>
<td>Parental Involvement</td>
<td>Assumptions</td>
<td>Social</td>
</tr>
<tr>
<td>Reviewer #3</td>
<td>Inconsistency</td>
<td>Consistent Expectations</td>
<td>Expectations</td>
<td>Peer Pressure</td>
</tr>
</tbody>
</table>

Furthermore, the comments made by the content reviewers regarding the results comprise
Table 2. The comments are helpful for examining differences between the participants’
responses. As an example noted in Question #1 that is displayed in Table 2, the patient (who uses
an insulin pump) fails to mention the pump as a method of glucose control, whereas the mom
and specialist both focus on this instrument. Again, the comments offered in Table 2 highlight
the disconnect in regard to mental status and morale, as the patient is more uncertain of her
ability to overcome management issues as compared to her mother and diabetes provider.
TABLE 2. Comments.

<table>
<thead>
<tr>
<th>Question #1</th>
<th>Question #2</th>
<th>Question #3</th>
<th>Question #4</th>
<th>Question #5</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Reviewer #1</strong></td>
<td>Emphasis was placed on insulin</td>
<td>Is energy the most vital component for a teenager that equals physical and</td>
<td>Is this lack of provider knowledge because she always deals with teen acceptance and she knows that they eventually have to accept</td>
<td>This is similar to the stages of grief, and the patient still goes back to denial.</td>
</tr>
<tr>
<td>administration as a way to manage.</td>
<td>administration as a way to manage.</td>
<td>mental health?</td>
<td>and then move on to more skill related things.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Provider has doubts</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Reviewer #2</strong></td>
<td>Everyone was on board with insulin</td>
<td>Interesting that energy is discussed as it is. Mom and daughter seem to</td>
<td>Seems to be a disconnect with the specialist as a major barrier perceived</td>
<td>Patient doesn’t seem confident in herself. Blame seems to be put on patient as mom says she “needs to realize this is her life,” and how outcomes “depend on how she chooses to manage her diabetes.” Is the patient in denial?</td>
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<td>as primary management, but only the</td>
<td>as primary management, but only the</td>
<td>take a holistic position on well being where provider focuses on one aspect.</td>
<td>by the parent and patient seems to be “not wanting to be diabetic anymore.”</td>
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<td>patient mentioned diet, and mom and</td>
<td>patient mentioned diet, and mom and</td>
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<td>specialist mention the pump.</td>
<td>specialist mention the pump.</td>
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<td><strong>Reviewer #3</strong></td>
<td>Patient included diet, and specialist</td>
<td>Patient and parent mention physical and mental. No mention of long term</td>
<td>The social piece is consistent. For the specialist the focus is on impact</td>
<td>Patient: Ambivalent, Frustration; Mom: Control; Provider: Patient/Family.</td>
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<td></td>
<td>noted pump.</td>
<td>sequelae.</td>
<td>of poor diet and dosing, whereas the parent and patient are giving up.</td>
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<td><strong>Question #6</strong></td>
<td>All answers are different but each</td>
<td>These are all different. The patient feels alone, the parent believes</td>
<td>Fascinating that the provider makes this judgement about the question.</td>
<td>Why did the pump not work if she didn’t want to be checking blood sugars all the time?</td>
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<td>skill mentioned is part of the</td>
<td>entire family, and the provider singles out the mom, again.</td>
<td>Very strong feelings from the provider about patients lack of involvement.</td>
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<td>management around insulin</td>
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<td>administration before meals.</td>
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<td><strong>Reviewer #2</strong></td>
<td>All participants think she is</td>
<td>Interesting response by the patient. It sounds like she is under the</td>
<td>Would be interesting to find out why this is thought to be a bad question.</td>
<td>Different responses. Highlights multifaceted aspect of disease management. It would be interesting to know what the provider means by “support.” Is this parental encouragement, or is it parental involvement?</td>
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<td>proficient in different aspects of</td>
<td>impression she is the only person with diabetes. In regards to the</td>
<td>Is the difficulty in management a social/friend issue, or a being away</td>
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<td>management.</td>
<td>consistent “mother” responses by the specialist, it makes one wonder how</td>
<td>from home issue?</td>
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<td><strong>Reviewer #3</strong></td>
<td>All results are different!</td>
<td>involved the father is with her cares.</td>
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<td><strong>Question #7</strong></td>
<td>All mom but patient and parent</td>
<td>Power statement by the patient. Patient versus family.</td>
<td>Eating with friends is a well know key factor/issue. Consider focus here.</td>
<td>Wonder about response, “Needs more family support.” There are variable responses. Patient – Immediate, Task; parent – Developmental; Provider – Family Focus.</td>
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<td>include dad.</td>
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<td><strong>Question #8</strong></td>
<td>Everyone agrees to the role the</td>
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<td>parents play in management.</td>
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<td><strong>Question #9</strong></td>
<td>All mom but patient and parent</td>
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<td></td>
<td>include dad.</td>
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<td><strong>Question #10</strong></td>
<td>Interesting response by the patient.</td>
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<td>It sounds like she is under the</td>
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<td>impression she is the only person</td>
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<td>with diabetes.</td>
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<td>In regards to the consistent “mother”</td>
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<td>responses by the specialist, it</td>
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<td>makes one wonder how involved the</td>
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<td>father is with her cares.</td>
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Interestingly, a disconnect in understanding where the patient is failing to adequately manage her diabetes was noted among the Patient, Mother and Endocrinologist. The Mother and Patient both emphasize the effect social and volatile environments such as being away from home have on her condition, whereas the Specialist believes the Patient’s problem is more of a will power and adherence issue.

**Summary**

The results section presents findings of the embedded case study. Table 1 displays themes as identified by the three content reviewers. Table 2 displays the brief comments that elicit differences that can be observed in the responses. The discussion section provides an interpretation of the results for the purposes of improving quality in the practice of nurse practitioners and other healthcare providers.

**DISCUSSION**

The insight obtained from this case study will allow nurse practitioners and health care providers to understand and adjust practices to accompany major elements of health behaviors (e.g., biological, psychological, sociocultural, etc.), which stand as foundations to encourage healthy lifestyles. With the information obtained, it is apparent that some of the management problems involved with the Patient, her Mother, and the Specialist relate to Pender’s theoretical propositions.

The responses were unique because the patient appears to be in denial regarding her diabetes, which is allowing her to develop characteristics that will negatively influence her views, affect, and enactment of health endorsing behaviors. Fortunately, her responses indicate that she understands that her diabetes management programs have personal benefit, which may
help her commit to engage in the behaviors required to gain control of her glucose. Her reported issue of “not wanting to be diabetic anymore,” which as Pender proposes, will constrain commitment to positive actions toward her health outcomes (Pender, 2011). It would be beneficial for the Endocrinologist to take a more holistic approach when managing this age group, so that she may able to address the stages of grief and development they endure at this arduous time.

The mother and specialist’s mindsets toward the patient’s competence and self-efficacy are positive in a sense that they believe she can control her diabetes, yet the endocrinologist reasons that she needs maturity to properly manage her condition. This may be a factor in the likelihood that she will not commit to proposed actions or undergo behavioral change. The patient’s perception that she will be able to overcome barriers is much lower than her Mom or provider’s, which according to Pender’s model, could be related to poorer results (Pender, 2011).

Furthermore, another proposition of Pender’s HPM is that a person is more likely to commit to and engage in health promoting activities when others demonstrate a desired behavior and require that same desired behavior to occur within the patient. This is an area where disconnect occurred between the parent and the specialist. Parental involvement was a common theme found within the results of the P4Q, however “involvement” was not conclusively defined. Based on the context, it seems that “parental involvement” is suggestive of more commitment in the day-to-day actions such as checking glucose, counting carbohydrates, and administering the proper dosage of insulin. Pender’s HPM is based upon the idea that all family, peers, and healthcare providers are key sources of effect that can either increase or decrease the devotion and engagement to health promoting actions.
Conclusion

Diabetes is and always will be a multi-faceted process with many dependent variables. This quality improvement project was designed to look at how Pender’s Health Promotion Model affects patient care even within an individual, especially how a rural adolescent and her involved mother with poor access to a distant diabetes specialist can obtain such poor outcomes. As we have found, there is a problem in this patient’s diabetes management. With the known adverse effects of diabetes on the human body, it is urgent that we address barriers to obtaining glycemic control in rural adolescent children. When being involved with a patient of this demographic, Pender’s HPM declares that the greater the commitment to a particular strategy or proposal of action, the more likely the health promoting behaviors are to be sustained over time (Pender, 2011).

This case is an ideal avenue to utilize anticipatory guidance to the patient and her mother, as well as other health care providers who are in collaboration. Patients need to be continuously educated so that they understand that diabetes is treatable, and that it is possible to obtain glycemic control. In addition, the family members, peers, and healthcare providers must take an active role and be involved in the adolescent patient’s cares. As we can see, it takes more than asking what a child’s blood glucose readings are, but more so the parents need to be asking “What is your plan for lunch today since you will be gone?” or “Show me how you count your carbs.”

This glimpse into a personal situation will allow other nurse practitioners and health care providers to understand that care plans and strategies must be well developed and thorough so
that this degree of disconnect does not occur within their health encounters. It is possible when using Pender’s HPM that this information has the ability to spread to other contexts.

For further study into this subject, it is suggested that criteria for the development of a customizable diabetes action plan be developed to assist in closing the gaps found between patient, parent, and provider when it comes to managing rural adolescent diabetes.
APPENDIX A:

PERCEPTION QUESTIONNAIRE [P4Q]
PATIENT QUESTIONNAIRE

1) What attempts have you made in the past to manage your diabetes?

2) What did you learn from these experiences?

3) What are the benefits to having your blood glucose be in range?

4) What problems do you have in trying to manage your diabetes?

5) On a scale from 1 to 10, with 1 being “uncertain” and 10 being “very sure”, how sure are you that you can overcome these problems to managing your diabetes? Why did you choose this number?

6) What do you believe you are the best at when it comes to managing your diabetes?

7) Who out of your family and friends expects you to keep your blood glucose in range?

8) Who encourages you to keep your blood glucose in range?

9) Who are your role models when it comes to managing your diabetes?

10) What are you doing when you find managing your diabetes is the most difficult?

11) What do you believe is the biggest challenge to committing to a plan that will better manage your diabetes?
PARENT QUESTIONNAIRE

1) What attempts has your daughter made in the past to manage her diabetes?

2) What did your daughter learn from these experiences?

3) What are the benefits for your daughter for having her blood glucose be in range?

4) What problems does your daughter encounter in trying to manage her diabetes?

5) On a scale from 1 to 10, with 1 being “uncertain” and 10 being “very sure”, how sure are you that your daughter can overcome these problems to managing her diabetes? Why did you choose this number?

6) What do you believe your daughter is the best at when it comes to managing her diabetes?

7) Who in your daughter’s circle of family and friends do you believe expect her to keep her blood glucose in range?

8) Who do you believe encourages your daughter to keep her blood glucose in range?

9) Who do you believe your daughter’s role model is when it comes to managing her diabetes?

10) What is your daughter doing when you believe she has the most difficulty managing her diabetes?

11) What you believe is your daughter’s biggest challenge to committing to a plan that will better manage her diabetes?
PROVIDER QUESTIONNAIRE

1) What attempts has this patient made in the past to manage her diabetes?

2) What did this patient learn from these experiences?

3) What are the benefits for the patient to have her blood glucose be in range?

4) What barriers does your patient encounter in trying to manage her diabetes?

5) On a scale from 1 to 10, with 1 being “uncertain” and 10 being “very sure”, how sure are you that your patient can overcome these barriers to managing her diabetes? Why did you choose this number?

6) What do you believe your patient is the best at when it comes to managing her diabetes?

7) Who in your patient’s circle of family and friends do you believe expects her to keep her blood glucose in range?

8) Who do you believe encourages this patient to keep her blood glucose in range?

9) Who do you believe the patient’s role model is when it comes to managing her diabetes?

10) What is this patient is doing when you believe she has the most difficulty managing her diabetes?

11) What do you believe is this patient’s biggest challenge to committing to a plan that will better manage her diabetes?
APPENDIX B:

PARTICIPATION EMAIL AND SURVEY LINK
PATIENT PARTICIPATION EMAIL AND SURVEY LINK

Dear Patient,

I am writing you today with the link to complete the questionnaire for the study entitled “Barriers and Challenges of Pediatric Type-1 Diabetes Mellitus Care in Rural Utah: A Case Study.” This goal of the study is to identify the beliefs of an adolescent Type-I diabetic patient, her mother, and the specialist as they pertain to the management of the patient’s condition. I hope you will be willing help us with our study.

By clicking on the link below and completing the survey, you agree to participate in the study. Should you agree to participate, it is anticipated that the survey will take approximately 45 minutes of your time.

As a reminder, participation in this study is completely voluntary. Your decision whether or not to participate will not cause you any harm. Your participation in this study will not lead to the loss of any benefits to which you have. Even if you begin the survey, you are free to stop and end participation at any time. You are not waiving any legal claims, rights, or remedies because of your participation in this research study.

If you have any questions prior to, during, or after the survey, feel free to call me (Sean) at ###-###-####, or email me at seanolsen@email.arizona.edu.

To begin your participation in the study, click the link below and privately answer each question in your own words with as much detail as possible.
Dear Parent,

I am writing you today with the electronic link to complete the questionnaire for the study entitled “Barriers and Challenges of Pediatric Type-1 Diabetes Mellitus Care in Rural Utah: A Case Study.” This aim of the study is to identify the beliefs of an adolescent Type-I diabetic patient, her mother, and the specialist as they pertain to the management of the patient’s condition. I hope you will be willing help us with our study.

By clicking on the link below and completing the survey, you imply your consent to participate in the study. Should you agree to participate, it is anticipated that the survey will take approximately 45 minutes of your time.

As a reminder, participation in this study is completely voluntary. Your decision whether or not to participate will not cause you any negative effect. Your participation in this study will not lead to the loss of any benefits to which you are otherwise entitled. Even if you begin the survey, you are free to stop and end participation at any time. You are not waiving any legal claims, rights, or remedies because of your participation in this research study.

If you have any questions prior to, during, or after the survey, feel free to call me (Sean) at ###-####, or email me at seanolsen@email.arizona.edu.

To begin your participation in the study, click the link below and answer each question in your own words with as much detail as possible.
Good afternoon Provider,

My name is Sean L. Olsen and I am currently completing the Doctor of Nursing Practice degree with the University of Arizona. I had the opportunity to speak with you a few weeks ago on the telephone and you mentioned you would be interested in assisting us with a project as it pertains to one of your patients, (name withheld). (Name withheld) and her mother has already agreed and is eager to participate.

As a reminder, the project is titled, “Barriers and Challenges of Pediatric Type-1 Diabetes Mellitus Care in Rural Utah: A Case Study.” Its goal is to help identify the perceptions of a pediatric rural T1DM patient, her parent, and the specialist as it pertains to her diabetes cares.

The extent of your involvement is your time (approx. 30 minutes) to complete an open-ended questionnaire that is located in the link at the bottom of this message. It will take you to a website called “Qualtrics,” an information collection website utilized by the University of Arizona.

Participation in this study is completely voluntary. Your decision whether or not to participate will not cause you any negative effect. Your participation in this study will not lead to the loss of any benefits to which you are otherwise entitled. Even if you begin the survey, you are free to stop and end participation at any time. You are not waiving any legal claims, rights, or remedies because of your participation in this research study.
REFERENCES


