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The Experience of Families Living with a Child with Type I Diabetes

Joni Franchini
Carroll College

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The Experience of Families Living with a Child with Type I Diabetes

Joni Franchini

Carroll College
This thesis for honors recognition has been approved for the Department of Nursing.
Abstract

The goal of aggressive treatment for type 1 diabetes mellitus is the prevention of chronic neuropathic complications that are most notably related to metabolic alterations of hyperglycemia. The purpose of this thesis is to develop a deep understanding of the lived experience among children and their families with type 1 diabetes in relation to care and knowledge of diabetic neuropathy. This is a qualitative study, based on phenomenological research, which describes experiences as they are lived. The study consisted of three families; each with a child diagnosed with type 1 diabetes for more than one year and one individual who developed type 1 later in life. The participants of the study described living with diabetes as affecting all aspects of life from activities, meal times, daily routines, and food provided in the home. Many of the families felt isolated and abandoned in maintaining care for their child with diabetes by healthcare providers; furthermore, knowledge related to complications was reflective of fear rather than understanding and prevention. Nursing implications for this study include increased support and education about acute and chronic complications of diabetes as well as access to new medications and care practice for families.
Acknowledgments

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To my parents, John and Julie Franchini,
And my practitioner, Cathie Hren...
And to my inspiration, Javelina.
Table of Contents

SIGNATURE PAGE......................................................................................................................2
ABSTRACT..................................................................................................................................3
ACKNOWLEDGMENTS..............................................................................................................4
TABLE OF CONTENTS...............................................................................................................6
CHAPTER I ......................................................................................................................................8
BACKGROUND ............................................................................................................................8
  Etiology ....................................................................................................................................9
  Risk Factors of Diabetic Neuropathy ...................................................................................11
  Disease Impact of Diabetic Neuropathy ..............................................................................13
  Psychosocial Impact of Diabetic Neuropathy ....................................................................14
CHAPTER II ................................................................................................................................16
REVIEW OF RESEARCH ..........................................................................................................16
  Conflicts between Young Adolescents with Type I and their Parents .............................16
  Foot Problems in Individuals on Hemodialysis .................................................................17
  Gender, Adolescence and the Management of Diabetes ......................................................18
  Patient Management of Long-Term Continuous Subcutaneous Insulin Infusion ..........20
  Self-Awareness Education Session for Youth with Type I Diabetes ...............................21
  Diabetes Nurse Case Management ....................................................................................23
  Summary .................................................................................................................................24
  Classification and Pathophysiology of Diabetic Neuropathy ...........................................25
  Classification and Disease Course ......................................................................................25
  Sensorimotor Neuropathy ....................................................................................................26
  Cardiovascular Autonomic Neuropathy .............................................................................27
  Gastrointestinal Autonomic Neuropathy ............................................................................27
  Genitourinary Autonomic Neuropathy ..............................................................................28
  Etiology ..................................................................................................................................28
  Pathology ...............................................................................................................................29
  Conclusion ...............................................................................................................................31
  Medications .............................................................................................................................31
  Diagnostic Tests ....................................................................................................................36
CHAPTER III ................................................................................................................................39
METHODOLOGY .........................................................................................................................39
  Design .....................................................................................................................................39
  Participants ...............................................................................................................................39
  Data Collection ......................................................................................................................40
  Data Analysis ..........................................................................................................................40
CHAPTER IV ...................................................................................................................................43
RESULTS/FACTS ..........................................................................................................................43
  Keeping Vigilance ..................................................................................................................43
  Challenging Lifestyle .............................................................................................................44
  Focusing Care ..........................................................................................................................46
  Coping with Diabetes ............................................................................................................46
CHAPTER V .....................................................................................................................................48
DISCUSSION .................................................................................................................................48
  Keeping Vigilance ..................................................................................................................48
  Challenging Lifestyle .............................................................................................................48
  Focusing Care ..........................................................................................................................49
Type 1 Diabetes

Coping with Diabetes .................................................................................................................................. 50
FUTURE RESEARCH .................................................................................................................................. 51
APPENDIX A: THEMES CHART .................................................................................................................. 53
APPENDIX B .................................................................................................................................................. 54
  Informed Consent Form ................................................................................................................................. 54
  Interview Template ......................................................................................................................................... 56
REFERENCES .................................................................................................................................................. 57

Type 1 diabetes mellitus is an autoimmune disorder characterized by the loss of beta cells in the pancreas. The incidence of type 1 diabetes mellitus is estimated to be 1 in 400 to 1 in 1000, and this population is directly related to the estimated 7.3 million dollars in permanent disability allowances for the nearly 200 million disability days, and whose direct health care cost was estimated to be $1.6 billion dollars in 2002 (Iqbal et al., 2002). It must be appreciated on prevention and education to help ameliorate the type 1 distribution in achieving and maintaining blood glucose control while limiting early-diagnosed diabetic disease with effective therapy and medication.

The goal of aggressive treatment for type 1 diabetes mellitus is the prevention of chronic complications, which are irrevocably related to glucose intolerance.
Chapter I

Background

The American Diabetes Association cites diabetes as one of the most common chronic diseases of childhood. It is estimated that about 176,000 children younger than 20 years of age, which is about one in every four to six hundred have type 1 diabetes (American Diabetes Association, 2008). The progressive disease process of type 1 diabetes mellitus can lead to multiple health problems and early death due to changes in macrovascular and microvascular circulation (Ignatavicius & Workman, 2006). Formerly known as insulin-dependent diabetes (IDDM), childhood diabetes, or juvenile-onset diabetes — type 1 diabetes mellitus is an autoimmune disorder characterized by the loss of beta cells in the islets of Langerhans in the pancreas that are destroyed by a genetically susceptible person’s immune system (Huether & McCance, 2004). The treatment and prevention of chronic complications of type 1 diabetes mellitus through education should be a precedent of health care providers.

The risk for type 1 diabetes mellitus ranges from 1 in 400 to 1 in 1000, and this population is among those that caused 7.5 billion dollars in permanent disability, accounted for nearly 88 million disability days, and whose direct health care cost was estimated to be 91.8 billion dollars in 2002 (Ignatavicius & Workman, 2006). Attention must be concentrated on prevention and education to help assist the type 1 diabetic client in achieving and maintaining blood glucose control while treating early-diagnosed chronic diseases with effective therapy and medication.

The goal of aggressive treatment for type 1 diabetes mellitus is the prevention of chronic neuropathic complications, which are most notably related to metabolic...
alterations of hyperglycemia. Prevention of diabetic neuropathy is crucial because even during periods of normal glycemic control, neuropathy develops as an initial clinical manifestation of diabetes. Through education and prevention therapies that promote circulation and cardiovascular health with consistent glucose control in therapeutic range, neuropathies are preventable and reversible (Huether & McCance, 2004).

Table 1 Preventable Neuropathies with Consistent Glucose (Ignatavicius & Workman, 2006).

<table>
<thead>
<tr>
<th>Painful peripheral neuropathy</th>
<th>Numbness or weakness with pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mononeuropathy</td>
<td>Wrist-drop, foot-drop</td>
</tr>
<tr>
<td>Diabetic amyotrophy</td>
<td>Muscular atrophy</td>
</tr>
<tr>
<td>Diabetic neuropathic cachexia</td>
<td>Weakness and wasting due to severe chronic disease</td>
</tr>
<tr>
<td>Visceral manifestations associated with autonomic neuropathy</td>
<td>Delayed gastric emptying, diabetic diarrhea, altered bladder function, orthostatic hypotension</td>
</tr>
</tbody>
</table>

Etiology

Type 1 diabetes mellitus accounts for 10% of all diabetes mellitus in the Western world. There is a factor of hereditary of 50% concordance rate in twins and between 10%-13% of newly diagnosed type 1 diabetics have a first-degree relative (parent or sibling) with type 1 diabetes (Huether & McCance, 2004). Prevalence is higher for whites than for non-whites, with the highest rate among those of Scandinavian descent than for those of central or southern European descent. Gender prevalence is similar between males and females. Interestingly more new cases are documented during fall and winter in the northern hemisphere (Huether & McCance, 2004).

The immune system cells and cell products fail to recognize normal body cells, taking defensive actions. The exact cause of type 1 diabetes mellitus is not known, but it is thought to be a result of a gene-environment interaction, with certain tissue types more
likely to develop autoimmune diseases—specifically HLA-DR3 or HLA-DR4 (Ignatavicius & Workman, 2006). Particular viral infections including mumps, congenital rubella, and coxsackievirus infections (enterovirus family of viruses which includes polioviruses and hepatitis A virus) seem to trigger the autoimmune destruction of pancreatic beta cells (Ignatavicius & Workman, 2006).

The etiology of diabetic vascular complications is presented in three theories consisting of:

(a) Irreversible structural changes related to chronic hyperglycemia resulting in basement membrane thickening and organ damage.

(b) Functional cell integrity affected indirectly/directly by glucose toxicity.

(c) Connective tissue hypoxia and microischemia caused by chronic ischemia in microcirculatory branches (Ignatavicius & Workman, 2006).

Diabetic neuropathy, a specific microvascular complication of blood vessel structure and function, is a progressive deterioration of nerves ensuing in a loss of nerve function. This common complication of diabetes involves all parts of the body: damage to sensory nerve fibers resulting in either pain or loss of sensation, damage to nerve fibers resulting in muscle weakness, and damage to nerve fibers in the autonomic nervous system resulting in widespread loss of many functions (Ignatavicius & Workman).

Diabetic neuropathy most commonly is diffuse, usually involving widespread nerve function loss on both sides of the body with a slow onset permanently affecting motor and sensory nerves (Huether & McCance, 2004). The most common cause of neuropathy in the Western world and the most common complication of diabetes is diabetic neuropathy (Huether & McCance, 2004). Nearly four million individuals in the United
States experience neuropathic pain (Chen, Lamer, Rho, Marshall, Sitzman, Salim et al., 2004).

Hyperglycemia, which produces advanced glycosylation end products, has been shown to lead to neuropathy through blood vessel damages that especially causes nerve degeneration and delayed conduction because of hypoxia (Huether & McCance, 2004). Sorbital, from excessive glucose, accumulates in the nerves reducing the blood flow from the axon and myelin sheath thus blocking nerve impulse transmission (Ignatavicius & Workman, 2006). Over 11.6% of insulin dependent diabetics develop diabetic peripheral neuropathy (Chen et al., 2004). Therefore, individuals with type 1 diabetes are at risk for diabetic neuropathy related to progressive diabetic condition as evidenced by long-term hyperglycemia and accumulating amount of time since diagnosis of type 1 diabetic mellitus.

**Risk Factors of Diabetic Neuropathy**

Features of diabetic neuropathy are divided between diffuse and focal, and differentiated by cause, rate of progression, and treatment (Ignatavicius & Workman, 2006). Diffuse is more common with diabetic neuropathy involving permanent widespread loss of nerve function, with slow onset and progression that affects both sides of the body and involves motor and sensory nerves. Including autonomic nerve dysfunction, late complications of diffuse neuropathy include foot ulcers and deformities (Ignatavicius & Workman, 2006).

**Diffuse neuropathy.** Diffuse neuropathies include distal symmetric polyneuropathy, which develops into sensory alterations and motor alterations in the intrinsic muscles of the foot (Ignatavicius & Workman, 2006). Manifestations of sensory
alterations include: (a) paresthesias (burning/tingling sensations starting in toes and moving up the legs), and (b) dysesthesias (burning, stinging, or stabbing pain), and anesthesia (loss of sensation). Motor alterations in intrinsic muscles of the foot result in foot deformities: high arc, claw toes, and hammertoes. Sensory neuropathy is the leading cause of foot disease among diabetic clients (Ignatavicius & Workman, 2006).

Autonomic neuropathy, another diffuse neuropathy, creates further complications listed in Table 2.

Table 2 Complications of Autonomic Neuropathy (Ignatavicius & Workman, 2006)

<table>
<thead>
<tr>
<th>Complication</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anhidrosis</td>
<td>Drying, cracking of skin</td>
</tr>
<tr>
<td>Gastroparesis</td>
<td>Delayed gastric emptying, constipation, nausea, anorexia</td>
</tr>
<tr>
<td>Diabetic diarrhea</td>
<td>Diarrhea and bowel incontinence</td>
</tr>
<tr>
<td>Neurogenic bladder</td>
<td>Atonic bladder, urine retention</td>
</tr>
<tr>
<td>Impotence</td>
<td>Erectile dysfunction</td>
</tr>
<tr>
<td>Loss of cardiac reflexes</td>
<td>Orthostatic hypotension, resting tachycardia</td>
</tr>
<tr>
<td>Defective counter-regulation</td>
<td>Loss of warning signs of hypoglycemia</td>
</tr>
</tbody>
</table>

_Focal neuropathies._ Focal neuropathies are usually caused by an ischemic event that affects a single nerve or nerve group (Ignatavicius & Workman, 2006). Either ischemic neuropathy or a physical trapping of a nerve can lead to nerve damage or nerve death.

Table 3 Manifestations of Focal Ischemia (Ignatavicius & Workman, 2006)

<table>
<thead>
<tr>
<th>Manifestation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thoracolumbar radiculopathy</td>
<td>Pain radiating across back, side, and front of chest or abdomen</td>
</tr>
<tr>
<td>Cranial nerve palsies</td>
<td>Third and sixth nerves resulting in sudden diplopia or ptosis</td>
</tr>
<tr>
<td>Amyotrophy</td>
<td>Pain; asymmetric weakness; wasting of iliopsoas, quadriceps, and adductor muscles</td>
</tr>
</tbody>
</table>

Symptoms occur suddenly, affecting only one side of the body, and transpire in self-limited intervals with varying recovery time.


**Entrapment neuropathies.** Stemming from the compression of a nerve that is located within tissues, entrapment neuropathies begin gradually and can exist anywhere (Ignatavicius & Workman, 2006). With no spontaneous recovery, entrapment neuropathies may be bilateral in either a waxing or waning course. Entrapment neuropathies include median nerve (carpal tunnel syndrome), popliteal nerve/knee (foot-drop), and posterior tibial nerve at tarsal tunnel (tarsal foot syndrome). Symptoms include sensory impairment in sole of foot, weakness of intrinsic muscles of foot, burning pain and paresthesias at ankle and plantar surface (Ignatavicius & Workman, 2006).

**Sensory alterations.** Clients with type I diabetes are also at risk for injuries related to sensory alterations in lower extremities. Foot injury is the most common reason for the hospitalization of a client with diabetes and diabetes is the leading source of amputations worldwide (Ignatavicius & Workman, 2006). An individual with diabetes is 15 times more likely to have an amputation, and clients with a previous amputation are 10 to 20 times greater to have a second amputation (Ignatavicius & Workman).

**Disease Impact of Diabetic Neuropathy**

The risk for foot ulcers and amputation related to diabetic neuropathy increases with poor glucose control as well as with the duration of diabetes placing type I diabetics in a higher risk category (Ignatavicius & Workman, 2006). Deborah Wilson, of the Wishaw General Hospital, stated, “The infection process is the main reason for major amputations following ulceration” concerning poor foot care (Wilson, 2005, p. 8). The likelihood of lower extremity amputation is 15-16 times higher in individuals with diabetes. In the United States alone more than 85,000 amputations are performed every year related to diabetic peripheral neuropathy (DPN) – 1 every 10 minutes (Harris, 2006).
Neuropathy is the most common chronic complications that nearly 50% of all clients with diabetes experience (Wilson, 2005). Prevention, early detection, and appropriate treatment are important in preventing amputations.

Chronic pain is another aspect of diabetic neuropathy acute nerve dysfunction that affects nearly four million people in the United States (Chen et al., 2004). “Neuropathic pain (NP) is initiated or caused by a primary lesion or dysfunction in the nervous system, commonly persists beyond the normal healing period, and exhibits symptoms of positive and negative sensory phenomena” (Chen et al., 2004, p. 1533). Stemming from neural dysfunction, long-lasting changes in the processing of sensory information by the nervous system are believed to underlie the presence of persistent neuropathic pain (Chen et al., 2004). Clients with diabetes may experience numbness, prickling, tingling, allodynia (pain after an innocuous stimulus/hyperesthesia), and pain, which are characterized as aching, burning, and lancinating (Harris, 2006).

Psychosocial Impact of Diabetic Neuropathy

The loss of independence and sense of uncontrolled circumstance that occur in the lives of individuals with diabetes adds additional stress to the daily demands of life. The National Service Framework for Diabetes is described as follows:

To maximize the quality of life of all people with diabetes and to reduce their risk of developing the long-term complications of diabetes’ which is ‘to ensure that people with diabetes are empowered to enhance their personal control over the day-to-day management of their diabetes in a way that enables them to experience the best possible quality of life. (Meetoo, 2004, p. 646)

Education is a cornerstone of diabetes management, but without determining an
individual’s ability to integrate the necessary behavior changes, knowledge alone is insufficient (Meetoo). Individuals that are empowered benefit both psychologically and physically in terms of maintaining long-term glucose control. When children are diagnosed with type 1 diabetes, consideration of the parents is vital because of how parent functioning affects child functioning. Bonner, Hardy, Guill, McLaughlin, Schweitzer, and Carter (2005) cited that subjective parent distress is an important factor in child outcomes. Failure to address the emotional, spiritual, social, and cognitive aspects of living with diabetes may lead to poor self-esteem, which initiates decreased motivation in self-care behaviors (Meetoo).
Chapter II

Review of Research

This section includes an analysis and brief summarization of quantitative and qualitative studies pertinent to the prevention and treatment of neuropathy in individuals with type I diabetes. The process of literature critique is important to the understanding and evaluation of applicable evidenced-based interventions acquired from research. This also allows further review of evidenced-based nursing implications that influenced the research design of this thesis.

Conflicts between Young Adolescents with Type I and their Parents

Conflicts between young adolescents with type I diabetes and their parents were similar to a non-distressed population in their ranking of quantity, intensity, and frequency by intensity scores (Viikinsalo, Crawford, Kimbrel, Long, & Dashiff, 2005). A descriptive study with 161 adolescents with type I diabetes and their parents utilized the Issues Checklist, specifically examining conflict. The sample was gathered from the first-year data collection of an ongoing cross-sectional, longitudinal study of families with adolescents who have type I diabetes.

The issues generating the highest frequency of discussion were comparable to those reported in the non-distressed group, with the exception of topics regarding what time to have meals and to watch television. Families of adolescents with type I diabetes scored lower than the comparable non-distressed group in all instances of significant differences. Disagreement may be present in other diabetes management-related areas that are not included in the Issues Checklist; moreover, this study did not address how these conflicts are negotiated or resolved. It is not known if these conflicts involve
maintenance of parent-adolescent relatedness with another, which can promote positive adaptations such as ego development and social perception skills (Viikinsalo et al., 2005).

Limitations exist in the study design because descriptive research restricts the ability to generalize to other populations. It is important to note that having type I diabetes does not heighten the usual developmental conflicts of adolescents with their mother overall. It is possible that higher levels of conflict over issues of diabetes management might still be related to poor self-management and worse metabolic control. Conclusions of the study also noted that having type I diabetes does not heighten normal developmental conflicts (Viikinsalo et al., 2005).

Information from this study could be used in evidenced nursing interventions to help families normalize those conflicts that are typical for families during this phase of development. Nurses working with adolescents with type I diabetes and their families should recognize, however, that conflicts might pose problems when they overlap with areas that are central to diabetes management (Viikinsalo et al., 2005).

Foot Problems in Individuals on Hemodialysis

Within the general public the prevalence of peripheral arterial occlusive disease (PAOD) is estimated between 3.5% and 23%. Among individuals with diabetes the prevalence of PAOD is 4 to 7 times greater. Of 125,000 annual lower extremity amputations, between 50% and 80% are attributable to diabetes; but most importantly between 50% and 85% of lower extremity amputations associated with diabetes can be avoided or delayed with proper education and treatment (Locking-Cusolito, Harwood, Wilson, Burgess, Elliot, Gallo, et al., 2005).

The purpose of the study was to identify the prevalence of risk factors that
predispose individuals on hemodialysis to foot problems as well as actual prevalence of amputations. Consisting of a one-time assessment of risk for and actual prevalence of amputations, the 232 subjects ranged from 21-91 years, mean age 65.1, 56% female, 44% male. Formal ethical review was not sought because the project was considered part of the program's continuous quality improvement process. The foot assessment instrument considered risk factors including age, gender, clinical comorbidities, anatomical deformities, laboratory values, smoking history, sensation, presence of pedal pulses by palpations, and capacity for self-care of feet. Study findings confirmed impressions that patients are at considerable risk for foot complications. Bivariate analysis indicated significant relationship between neuropathy and both increased incidence of foot ulceration (p=.04) and absence of pedal pulses (p=.034). The relationship between self-care behaviors and foot ulcers or amputations was not found to be statistically significant (Locking-Cusolito et al., 2005).

Limitations of this study included that the sample was limited to patients in one health department program in a large, urban, academic area; participants were mainly native Canadians and the demographics do not reflect other dialysis centers; data were collected by several individuals contributing to problems with inter-rater reliability. Implications for nursing practice included regular screening for foot problems, comprehensive education for self-care, and referral algorithm to delineate patients to specialists when required (Locking-Cusolito et al., 2005).

*Gender, Adolescence and the Management of Diabetes*

Gender, adolescence and the ways in which young people assimilated or rejected diabetes in terms of their identities have major implications in how they manage their
treatment regimens (Williams, 1999). Four specific themes throughout the study included the following: the gendered meanings of diabetes, gendered management strategies, gendered dependencies, and adherence to treatment regimes. The ways in which gender impacts on the meanings and the management of diabetes during adolescence were derived from a qualitative study. The commonly recognized transitional age range of 15-18, when young people are moving towards independence, was the narrowly chosen age range (Williams, 1999).

Girls injected themselves in public settings, reflecting the fact that for them diabetes was part of their identity. Boys were much more likely to choose a regimen which enabled them to manage their diabetes from home, in private. A crucial factor in gendered dependencies enabling boys to manage their diabetes was the practical and emotional help and support of their mothers. Higher expectations were placed on girls to be independent in their care. Regarding non-adherence to regimens, adult women showed a greater adaptability to illness, and were far less likely to attempt to recapture their past selves once they had defined physical changes as permanent. Participation in the study was voluntary; anonymity and confidentiality were guaranteed. Interviews were conducted separately with mothers and the young people in their homes. The interview consisted of a series of prompts relating to topics such as treatment, stigma, and gender, and this was updated as new areas for discussion emerged from interviews. A grounded theory approach was taken, which allowed themes and concepts to emerge from the data and inform the theoretical framework (Williams, 1999).

The selection process and lack of diversity restricts the ability to assume these results for a population. Teenage girls and boys differ as to whether or not they
Type 1 Diabetes

assimilated diabetes into their identities. Health professionals should be aware of the pressures girls feel to take over self-care. Girls may be more likely to hide non-adherence and adaptations of regimens, as well as to have consequent feelings of guilt and self-blame. Girls may lower their expectations for themselves, which can result in poorer control of blood glucose levels. Masculine ways of managing chronic disease could be very advantageous. It is also very important to recognize that the emphasis health professionals place on young people’s independence in self-care can place mothers in a very difficult, ‘no-win’ situation (Williams, 1999).

*Patient Management of Long-Term Continuous Subcutaneous Insulin Infusion*

The importance of intensive therapy to achieve near-normoglycemia and long-term health in type-1 diabetes is highlighted in continuous subcutaneous insulin infusion (CSII). Researchers have found that CSII does facilitate nocturnal glycemic control and improved participants’ lifestyles. CSII requires a motivated individual with a range of technical skills and self-management capabilities; thus it is important to monitor patients’ management of pumps (Johansson, Adamson, Lins, & Wredling, 2005).

The purpose of the study was to report current patient’s practice with continuous subcutaneous insulin infusions in respect to management of the pump. The method consisted of a questionnaire developed by the authors, was mailed to 102 patients at a Swedish university hospital that received continuous subcutaneous insulin infusion treatment through pump therapy for greater than six months. Nine questions covered treatment practices, and two pertained to problems with CSII therapy like catheter occlusions and bleeding at the infusion site. The sample included 53 women and 37 men, between the ages of 22-71 with continuous subcutaneous insulin pump therapy use
between 7 months and 19 years (Johansson, Adamson, Lins, & Wredling, 2005).

Results included a higher occurrence of occlusions in patients with lispro insulin than with human insulin and among those who reported bleeding at the infusion site. Concerning use of lispro insulin, patients had a tendency to change their reservoirs more often than those with human insulin. Patients change their infusion sites and insulin reservoirs less frequently than recommended by protocol (Johansson, Adamson, Lins, & Wredling, 2005).

Possible reporting bias, as well as comparing data from different types of studies of treatment problems that lack a universal definition of "catheter occlusion" reflects limitations of this study. Nursing implementation encompassed promoting shorter intervals between changes of infusion sets and the type of insulin preparations. Future research in this area would benefit from a universal definition of "catheter occlusion," as well as the development of a questionnaire to take into account the patients' attitudes and opinions concerning the practical aspects of insulin pump therapy (Johansson, Adamson, Lins, & Wredling, 2005).

Self-Awareness Education Session for Youth with Type 1 Diabetes

"Chronic complications from diabetes relate to virtually every organ in the body and result in morbidity, premature disability, and mortality, all of which exert major disruptions and negative effects on personal, family, social, and work life" (Hernandez & Williamson, 2004, p. 459). However, good glycemic control achieved through intensive diabetes management can decrease, delay, and prevent complications of retinopathy, nephropathy, and neuropathy. Nonetheless, many factors work to inhibit client achievement of glycemic control including the extent of the intrusiveness of diabetes
regimen activities and the number of variables that influence glycemia that are not recognized by clients or their care providers (Hernandez & Williamson, 2004).

The research study was designed to evaluate the effectiveness of a short educational intervention to increase self-awareness of adolescents and young adults with type 1 diabetes. The study was organized within the Hernandez’ theory of integration, which originated from grounded theory studies of type 1 diabetic adults. The aspects of integration in this intervention study were the significance of self-awareness through recognizing body cues that result from various levels of glycemia, the admission of client expertise in detection and monitoring of these cues, and collaborative alliance education method for the study intervention (Hernandez & Williamson, 2004).

The self-awareness educational intervention consisted of observation of a video on self-awareness that described self-awareness and featured diabetic clients describing the symptoms they experience with varying levels of glycemia. The setting for the study was a retreat center in Ontario. A convenience sample consisted of 29 adolescents and young adults that were in attendance at a diabetes youth weekend. The study questionnaire was given before and immediately after the self-awareness educational intervention, as well as later mailed to participants for a one year post-intervention (Hernandez & Williamson, 2004).

Participants reported additional changes in thinking or behavior over the year following the educational intervention. Through participants’ depiction of their blood glucose cues the researchers learned new cues for the different levels of glycemia that are not normally identified in textbook lists. This research confirmed that a short education session can have an advantageous short and long-term influence on knowledge of self-
awareness regarding glycemia as well as that a one-hour self-awareness intervention can have short- and long-term benefits for adolescents and young adults ($p < 0.05$ significance level). Nursing implications included identified necessary changes in nursing assessment criteria to add assessment of the specific cues for various levels of glycemia as well as revisions in diabetes education curricula to include instruction in self-awareness techniques and strategies (Hernandez & Williamson, 2004).

**Diabetes Nurse Case Management**

Tight glycemic control and well-coordinated disease management are vital to improve patient quality of life, decrease hospitalizations and associated costs with the disease, and reduce the risk of long-term complications. The purpose of this study was to observe if there is a sustained improvement in diabetes management measures at enrollment, discharge, and six months after discharge from the nurse case management program. A tertiary military medical treatment facility (MTF) put into effect a diabetes nurse case management program in March 2000, intended for patients with type 1 or type 2 diabetes mellitus with a hemoglobin A1c value of 8.0% or greater. Following completion of a diabetes group education program with individual counseling, patients were observed quarterly through laboratory studies and physician visits for one year following the training program (Mullen & Kelley, 2006).

The theoretical framework used was Orem’s Theory of Self-Care because it supported the active role advanced practice nurses (APNs) play in assisting patients with diabetes develop self-management strategies. A convenience sample of 53 medical records (37 men and 16 women, age range 29–80 years, with a mean age of 60 years) met the inclusion criteria which included (a) medical records from patients who were coded
with ICD-9 code diabetes and (b) medical records from patients who were discharged from the diabetes nurse case management program after successful completion of the program as indicated by achievement of an $A_1C$ of 7.0% or lower (Mullen & Kelley, 2006).

A total of 19 records had complete data (laboratory values) and were analyzed with descriptive statistics and paired t-test performed using Statistical Program for the Social Sciences. A significant change occurred ($p < .005$) in the $A_1C$ mean value between admission and discharge as well as admission and six months following discharge. Through the stability of the mean between discharge and six months following discharge, a significant finding denoted that patients sustained diabetes management after discharge from the case management program (Mullen & Kelley, 2006).

One limitation was absent data for essential measures that limited the type of statistical procedures that could be completed. Data were absent because of failure to have the laboratory work ordered, failure to have the laboratory work completed by the patient, and values that were unable to be located (Mullen & Kelley, 2006).

Nursing implementations include a need to develop a system for tracking patient laboratory studies. Of the 53 patients, 18 patients did not have laboratory tests ordered by the provider; although $A_1C$ value retested every six months once a value of 7% is attained. Furthermore, continuing education in diabetes self-management is important to maintain positive outcomes and reduce the risk of long-term complications (Mullen & Kelley, 2006).

**Summary**

Diabetic neuropathy is a many-faceted complication of diabetes that can be
managed symptomatically. The best evidence suggests that near-normal control of blood glucose in the early years after the onset of diabetes may delay the development of clinically significant nerve impairment. Education is a cornerstone of diabetes management, but without determining an individual’s ability to integrate the necessary behavior changes, knowledge alone is insufficient. Intensive insulin therapy to achieve normalization of blood glucose may also lead to reversibility of early diabetic neuropathy.

Classification and Pathophysiology of Diabetic Neuropathy

Recognized as a leading complication that results in significant morbidity and mortality, neuropathy of type I diabetes mellitus is related to the development of macrovascular and microvascular complications (Feldman, 2003). Diabetic neuropathy is considered a heterogeneous condition that can be manifested by obvious symptoms or subclinical abnormalities detectable early only by careful testing (Trotta, Verrotti, Salladini, & Chiarelli, 2004). Feldman, of the Juvenile Diabetes Research Foundation Center states “[g]reater than half of all patients with diabetes develop neuropathy, a progressive deterioration of nerves resulting in peripheral and autonomic nerve dysfunction” (Feldman, 2003, p. 431). With electrophysiological evaluation, 57% of children and adolescents have subclinical neuropathy, in which the duration of diabetes only increases the risk of neuropathy, and the emphasis of neuropathy management only remains prevention by glycemic control (Trotta et al., 2004; Duby, Campbell, Setter, White, & Rasmussen, 2004).

Classification and Disease Course

Diabetic neuropathy is largely classified by the nerve fibers affected, which
includes sensory, autonomic, and motor neurons of the peripheral nervous system. Furthermore, all organ systems that rely on innervation to function are consequently subject to pathology. Clinical neuropathy is defined as “an abnormal neurologic examination consistent with peripheral sensorimotor polyneuropathy plus either abnormal nerve conduction to at least two peripheral nerves or unequivocally abnormal autonomic nerve testing (Trotta et al., 2004; Duby et al., 2004). Diabetic neuropathy is described through the unique syndromes that are principally categorized by the nerve fibers influenced.

*Sensorimotor Neuropathy*

The primary risk factor for the development of a diabetic foot ulcer, sensorimotor neuropathy, or distal symmetrical polyneuropathy is what most health care providers acknowledge as diabetic neuropathy. The damage usually develops insidiously as the change of sensations is detected accompanied by excruciating, refractory pain (Duby et al., 2004). Affecting large and small afferent nerve fibers, sensorimotor neuropathy results in mixed symptoms. Large afferent nerve fibers convey cold, proprioception, and vibration sensation. Small afferent nerves, which conduct nociceptive stimuli, touch, and warmth sensation manifest as pain and paresthesia. “Manifestations of sensorimotor neuropathy classically progress from the most distal extremities (the fingers and toes) in a symmetrical pattern that is generally described as a glove-and-stocking distribution” (Duby et al., 2004, p. 161). Most patients describe the positive symptoms as burning, tingling, aching, cold sensation, lancinating pain, numbness, or pain from normal touch (allodynia). However, the negative symptoms of sensory loss are more common and will occur in the course of diabetes manifesting as an inability to feel, identify or manipulate
small objects, and incapacity to judge temperatures (Duby et al., 2004).

Cardiovascular Autonomic Neuropathy

Rapidly emerging as the key cause of morbidity and mortality in diabetes, cardiovascular autonomic neuropathy (CAN) has an incidence around 15% in type I diabetic patients. Duby, Campbell, Setter, White, & Rasmussen (2004) hypothesized in a therapeutic update on diabetic neuropathy that “the comorbidity of CAN with coronary artery disease results in synergistic cardiovascular dysfunction, decreased myocardial infarction survival rates, and increased incidence of malignant arrhythmia and sudden death” (p. 162). CAN does affect the sympathetic and parasympathetic innervation of the heart and coronary vessels with characteristic symptoms of orthostatic hypotension and decreased heart rate variability which contributes to left ventricular dysfunction, silent or asymptomatic myocardial infarction, and exercise intolerance (Duby et al., 2004). CAN is reflected by the duration of ventricular myocardial polarization and repolarization by the prolongation of the QT interval on EKG (Trotta et al., 2004).

Gastrointestinal Autonomic Neuropathy

The most common GI complication associated with diabetes is gastroparesis, but diabetic autonomic dysfunction can affect the entire system from esophagus to colon. Symptoms typically occur later in the course of diabetes and range from mild discomfort to disabling impairment. Gastroesophageal reflex disease (GERD) is a manifestation of gastroesophageal dysfunction in 30% of patients with diabetes (Duby et al., 2004). Gastric retention and delayed gastric emptying—which are present in 25-50% of patients of diabetes—are typically the cause of early satiety, cramping, bloating, epigastic pain (heartburn), nausea and vomiting, and anorexia. Nearly 25% of patients have
symptomatic colon abnormalities that result in severe constipation, diarrhea, and fecal incontinence (Duby et al., 2004).

**Genitourinary Autonomic Neuropathy**

Sexual function and urinary continence are also adversely affected by diabetes. The inability to sense bladder fullness or initiate micturition, which results in urinary retention, bladder enlargement, and overflow incontinence may be caused by diabetic autonomic neuropathy (Duby et al., 2004). Erectile dysfunction affects 50% of men over 50 years old with diabetes. Complete impotence may result from neuropathic dysfunction that leads to a gradual loss of rigidity. Female sexual dysfunction is commonly manifested as a diminished libido that results in vaginal dryness and pain during intercourse (dyspareunia) (Duby et al., 2004).

**Etiology**

Although the etiopathogenesis of diabetic neuropathy is not fully understood, the dysfunction of blood vessels supplying the peripheral nerves was the first association of this complication. Studies suggest that absolute or relative ischemia may exist in the nerves of diabetic subjects because of altered function of endoneurial or epineurial blood vessels (Trotta et al., 2004). However:

...experimental studies in animals and humans demonstrated that hyperglycemia *per se* plays an important role in the pathogenesis of DN and also the 6-yr. nationwide cohort of glycemic control in young people with T1DM emphasizes the need for optimal glycemic control in children and adolescents with diabetes. (Trotta et al., 2004, p. 48)

Tissue damage caused by hyperglycemia can be adjudicated by the outcome of polyol
pathway activation with the buildup of sorbitol and fructose in nerves, damaging them by an unknown mechanism and by non-enzymatic glycation (Trotta et al., 2004). The four major pathways for glucose metabolism in the condition of hyperglycemia “become perturbed as a direct or indirect consequence of hyperglycemia-mediated superoxide overproduction by the mitochondrial electron transport chain” leading to the development of microvascular complications resulting in diabetic neuropathy (Feldman, 2003, p. 431).

Pathology

The focuses of current diabetic neuropathy research are oxidative stress, advanced glycation end products (AGEs), and the polyol pathway (PKC). The pathology of peripheral nervous and microvascular systems is inseparably intertwined — blood vessels depend on neural regulation for normal function, and neurons depend on capillaries for nutrients. “Diabetic neurovascular disease is a metabolic disorder, and the key to pathogenesis is that neither vascular nor nervous tissue requires insulin for the uptake of glucose” (Duby et al., 2004, 162). Consequently, hyperglycemia results in elevated intracellular glucose levels that drive secondary pathologies — oxidative stress and protein glycation by the accumulation of sorbitol and fructose in nerves. The first pathological change is a physiological shift toward vasoconstriction that is evidenced by blunted vasodilation and elevated vasoconstrictor activity. Vascular abnormalities like capillary basement membrane thickening and endothelial hyperplasia that contribute to diminished oxygen tension and hypoxia correlate closely with neuronal dysfunction of nerve degeneration, consisting of edema, myelin swelling, and axogial disjunction. (Trotta et al., 2004; Duby et al., 2004).

Oxidative stress. Diabetes is a hypermetabolic state that produces elevated
intracellular concentrations of glucose that can contribute in a number of different pathological processes. Sugar reacts with reactive oxygen species to form carbonyls that can further react with proteins or lipids, producing glycoxidation or lipoxidation compounds. Glucose and its metabolites can also create carbonyl complexes with proteins directly producing AGEs that also contribute to oxidative stress (Duby et al., 2004). Increased levels of glucose may also lead to increased production of reducing agents (i.e., NADH and FADH$_2$) that are involved in glycolysis and the tricarboxylic acid cycle. The surplus of electron donors develops an imbalance of the electron transport chain of the mitochondria accelerating the production of superoxide, which is a highly reactive free radical (Duby et al., 2004).

*Advanced glycation end products (AGEs)*. Glucose and other sugars nonenzymatically form covalent bonds with proteins. Although this process occurs in euglycemic individuals and usually affects only longer-lived proteins, hyperglycemia provides an excess of substrate and accelerates the reaction altering essential protein structure and impairing function (Duby et al., 2004). Scattered evidence links AGEs to abnormalities in vascular tissue, lipid metabolism, and platelets that may be germane to the pathology of diabetic neuropathy (Duby et al., 2004).

*Polyol pathway flux*. Essentially an alternative catabolic pathway that is activated and supplied by elevated intracellular glucose levels, the polyol pathway provides persuasive indication that chronic hyperglycemia can induce and drive subordinate metabolic processes that promote intracellular instability and decay (Duby et al., 2004). The first redox reaction of the polyol pathway couples the reduction of glucose by the enzyme aldose reductase with the oxidation of NADPA to NADP$^+$ that produces sorbitol.
Sorbital is further oxidized to fructose and coupled with the reduction of NAD$^+$ to NADH. It is not the sorbital concentrations, but the high rate of flux of glucose though the polyol pathway that is pathogenic and contributing to the oxidative stress and the accumulation of toxic species (Duby et al., 2004).

**Conclusion**

Diabetic neuropathy is a many-faceted complication of diabetes that can be managed symptomatically. The best evidence suggests that near-normal control of blood glucose in the early years after the onset of diabetes may delay the development of clinically significant nerve impairment. Intensive insulin therapy to achieve normalization of blood glucose may also lead to reversibility of early diabetic neuropathy.

**Medications**

Over 30% of patients with neuropathy have intractable pain (Chen et al., 2004). The advancing knowledge of neuropathy mechanisms has not led to the discovery of the ideal mechanism-based treatment. It is challenging for a clinician to distinguish between neuropathic and nociceptive pain. Furthermore, the clarification of cognitive and behavioral dimensions of a patient's pain is an important step toward individualizing therapy. Current evidence gained from randomized clinical trials has developed a list of first-line pharmacotherapy agents for treatment of neuropathic pain including the following: tricyclic antidepressants (TCAs), anticonvulsants, and narcotic analgesics (Chen et al., 2004). When choosing a pharmacotherapy agent, it is important for the clinician to weight the efficacy of each, adverse effects, the specific type of neuropathic disorder, and any comorbidity.
Tricyclic antidepressants. The mechanism of action for tricyclic antidepressants is possibly the sodium channel blockade and the facilitation of endogenous inhibition of pain (Chen et al., 2004). Another source suggested the TCAs inhibit the re-uptake of noradrenaline and serotonin as well as alter the mode of action of alpha 1 adrenergic receptors, which reduces sympathetic activity and blocks hyperalgesia induced by NMDA receptors (Spruce, Potter, & Coppini, 2003). Promoting analgesia to thermal, mechanical and electrical stimuli in diabetic patient studies recommend that TCAs be given primarily for burning pain symptoms. Evidence has suggested that first-line agents with adrenergic or mixed serotonergic and adrenergic mechanisms are more effective than selective serotonin reuptake inhibitors. TCAs are more lethal in situations of overdose than other antidepressants with many intolerable side effects related to anticholinergic action including the following: sedation, blurred vision, dry mouth, orthostatic hypotension, and cardiac arrhythmias (Spruce, Potter, & Coppini, 2003). Desipramine, amitriptyline, imipramine, and clomipramine are stated by Duby et. al to have demonstrated the best efficacy (2004). In prescribing a TCA the decision should be based on the individual patient’s tolerance and the risk of adverse side effects. Current prescribing trends promote TCAs such as trimipramine and amitryptyline; however, an effective response is delayed between 2-3 weeks and an effective therapeutic dose differs between patients.

A tricyclic antidepressant (TCA) that exhibits a sedative property has been shown to promote neuronal activity by blocking the membrane pump mechanism, which is responsible for the absorption of serotonin and norepinephrine in serotonergic and adrenergic neurons. Common trade names are Elavil and Vanatrip. Polyneuropathy doses
are as follows: 10-25 mg orally at bedtime; may increase at weekly intervals to a max
dose of 150-200 mg/day. It is important to monitor reduced depression and associated
symptoms, blood pressure, ECG in patients with cardiac disease or hyperthyroidism,
worsening of depression, suicidality, or unusual changes in behavior, especially at the
initiation of therapy or when the dose increases or decreases. Common side effects are
the following: weight gain, bloating, constipation, asthenia, dizziness, headache,
somnolence, blurred vision, and fatigue.

**Selective serotonin re-uptake inhibitors.** A subclass of antidepressants that
functions by possessing specificity for the presynaptic re-uptake of serotonin, SSRIs have
reduced side effects associated with TCAs (Spruce, 2003). Mode of action is based
around experimental observations that serotonin is an important mediator of analgesia.
Clinical studies of SSRIs are limited to the treatment of sensorimotor neuropathy. The
Food and Drug Administration has recently approved Duloxetine, a potent SSRI that has
shown effective in treating pain caused by diabetic neuropathy at doses of 60 mg and 120
mg daily. Nonetheless, SSRIs are considered less effective than TCAs although they are
better tolerated with reduced adverse side effects (Duby et al., 2004).

A selective serotonin and norepinephrine reuptake inhibitor (SSNRI), duloxetine
HCL, trade name Cymbalta, causes antidepressant and pain inhibitory actions by
facilitating the serotonergic and noradrenergic activity in the CNS. One of the FDA
labeled indications is for diabetic neuropathy pain with dosage 60 mg orally once daily. It
is important to monitor diabetic peripheral neuropathic pain through use of a pain scale
score, as well as reduction or improvement of depression and associated symptoms blood
pressure, liver function, ocular pressure, and withdrawal symptoms (e.g., dysphoric
mood, irritability, agitation, sensory disturbances). Common adverse side effects include the following: cardiovascular palpitations, diaphoresis, constipation, decrease in appetite, diarrhea, nausea, xerostomia, asthenia, dizziness, insomnia, somnolence, vertigo, blurred vision, increased frequency of urination, cough, and fatigue (Duby et al., 2004).

Anticonvulsants. Neuropathic pain is distinguished by a neuronal hyperexcitability in damaged areas of the nervous system, which exhibit abnormal spontaneous and increased evoked activity due to an increased and novel expression of sodium channels (Chen et al., 2004). Molecular changes cause abnormal expression of sodium channels, increased activity at glutamate receptor sites, changes in gamma-aminobutyric acid (GABA-ergic) inhibition, and an alteration of calcium influx into cells. The molecular changes then cause peripheral hyperexcitability at the peripheral nociceptor level in the dorsal root ganglia, in the dorsal horn of the spinal cord, and in the brain. The common features between neuronal hyperexcitability and the corresponding molecular changes in neuropathic pain have led to the use of anticonvulsant drugs for the treatment of neuropathic pain (Chen et al., 2004).

Recognized widely as an effective treatment of sensory neuropathic pain, the exact mechanism of action of Neurontin or Gabarone (trade name) is not known. Although the analgesic action is unknown, gabapentin prevents pain-related behavior in response to a normally innocuous stimulus (alldynia) and exaggerated response to painful stimuli (hyperalgesia). Pain-related responses after peripheral inflammation were also decreased by gabapentin. Immediate pain-related behaviors were not altered by gabapentin (Duby et al., 2004). A non-FDA labeled indication is for diabetic peripheral neuropathy with dosage of 900-3600 mg/day orally in 3 divided doses. Usually well-
tolerated, doses of gabapentin are most effective at 1800 mg or more daily, rapid titration increases the incidence of central nervous system side-effects. Gabapentin has a higher rate of sedation and dizziness than amitriptyline, a TCA (Duby et al., 2004). However, in clinical studies gabapentin has been proven to have statistically significant efficacy in reducing pain severity in global impression scales and quality-of-life assessments (Duby et al., 2004). It is important to monitor seizure control and postherpetic neuralgia pain assessments. Common adverse side effects include the following: cardiovascular peripheral edema, myalgia, dizziness, nystagmus, somnolence, tremor, mood swings, and fatigue.

Known by the trade name Lyrica, pregabalin has FDA labeled indications for diabetic peripheral neuropathy. The mechanism of action is a GABA analog that strongly binds to the alpha(2)-delta site that may be involved in pregabalin's effects on neuropathic pain and seizure control (Duby et al., 2004). Reducing the calcium-dependent release of several neurotransmitters, possibly by modulation of calcium channel function, the exact mechanism of action is unknown. Initial dosage is 50 mg orally three times a day (150 mg/day) and may be increased to 100 mg orally three times a day (300 mg/day) within 1 week based on efficacy and tolerability (Duby et al., 2004). It is important to monitor partial onset seizures, diabetic peripheral neuropathy pain assessments, creatinine kinase, with occurrence of myopathy symptoms such as malaise, fever, or muscle pain, platelet count. Common adverse effects include the following: cardiovascular peripheral edema, weight gain, constipation, xerostomia, ataxia, dizziness, somnolence, blurred vision, diplopia, and disturbance in thinking (Duby et al., 2004).

*Narcotic analgesics.* An opioid is a chemical substance that has a morphine-like
action in the body. By binding to opioid receptors, which are found principally in the central nervous system and the gastrointestinal tract, opioids appear to block A delta fiber- and C fiber- mediated pain but may be less likely to reduce A beta fiber- mediated mechanical allodynia. Additionally, some opioids antagonize the NMDA receptor (Chen et al., 2004). There has been an increased use of opioids in the management of non-malignant chronic pain, including that of diabetic neuropathy.

Tramadol HCl is a centrally acting opioid analgesic that exerts its effect through the inhibition of norepinephrine and serotonin reuptake, presenting as an effective medication for neuropathic pain. Known through the trade names Ultram and Ultram ER one of the FDA labeled indications is for chronic pain: moderate to moderately severe. Dosages for chronic pain are the following: (immediate-release) titration schedule, 25 mg/day orally every morning, titrated in 25 mg increments as separate doses every 3 days to reach 25 mg 4 times daily; then, may increase total daily dose by 50 mg as tolerated to reach 50 mg 4 times daily; after titration, 50 to 100 mg orally every 4-6 as needed can be used (Duby et al., 2004). The max dosage is 400 mg/day. Tramadol is a safe and effective medication for diabetic sensorimotor neuropathy, although the dosage required to reach therapeutic levels is relatively high (Duby et al., 2004). It is important to monitor the following: pain reduction, improvement in ability to move, mental and respiratory status, bowel movements, signs and symptoms of withdrawal. Common adverse side effects include the following: pruritus, constipation, diarrhea, nausea, vomiting, dizziness, headache, and somnolence (Duby et al., 2004).

Diagnostic Tests

Hemoglobin Alc measurement. This test monitors diabetes treatment by
measuring the amount of hemoglobin A₁C (HbA₁C) in the blood, providing an accurate long-term index of the patient’s average blood glucose level. In adults, about 98% of the hemoglobin in the red blood cells (RBCs) are hemoglobin A. About 7% of hemoglobin A consists of a type of hemoglobin (HbA₁C) that can combine strongly with glucose in a process called glycosylation, which once occurs is not easily reversible. The amount of glycosylated hemoglobin depends on the amount of glucose available in the bloodstream over the RBC’s 120-day life span. This sample can be drawn at any time because it is not affected by short-term variations. The management goal is a hemoglobin HbA₁C level less than 7%, which is an average mean plasma glucose of 135 mg/dl (Pagana & Pagana, 2007).

*Semmes-Weinstein monofilament examination.* The 5.07 monofilament is applied to ten sites per foot until it buckles (distal great toe, third toe, and fifth toe; first, third, and fifth metatarsal heads; medial foot, lateral foot, and heel), and then held for 1 second. It is important to first demonstrate the monofilament sensation on one of the individual’s hands. Using a two-choice forced algorithm, each site is touched once during one of two time periods, while counting “one, two.” The individual is asked to state the time interval (1 or 2) during which the stimulus is felt, or to state that he or she could not tell. The Semmes-Weinstein 5.07 monofilament examination is recommended as a diagnostic test of choice for the detection of diabetic patients with feet at risk of ulcers and amputation (Smieja et al., 1999).

*Vibration testing by the on-off method.* Vibration sensation was tested with a 128 or 256 Hz tuning fork over the distal big toe and medial malleolus. The fork is struck gently against the palm so that vibration could be felt for 10 to 15 seconds. Before the test
is initiated, the sensation should be demonstrated on the patient’s sternum or patella. Patients are asked initially, and after 5 seconds, whether they perceived vibration. When vibration is felt both initially and after 5 seconds, the patient is scored as normal (Smieja et al., 1999).

Superficial pain sensation testing. Using a sterile or unused safety pin over the plantar aspect of the distal first, third, and fifth toe of each foot the stimulus is applied once per site. Patients are then asked to identify when they felt the sensation, and whether it was sharp or dull (Smieja et al., 1999).

Overall, in the treatment and diagnosis of diabetic neuropathy annual screening should be performed using superficial pain sensation testing such as Semmes-Weinstein monofilament examination (SWME) or vibration testing by the on-off method. The reported distinctiveness for each sensory function can be applied to findings on the physical examination of individual patients to diagnosis a risk for neuropathy (Perkins, 2001). Individuals are usually diagnosed with diabetic peripheral neuropathy when two of the following three criteria from both legs were met: (1) the presence of pain, numbness, or paraesthesia; (2) a diminished or absent ankle reflex; or (3) a scale below 4 for their vibration perception thresholds (VPT) (Smieja et al., 1999). Continued diabetic education and re-edification of good glycemic control is pertinent to the prevention of diabetic neuropathy.
Chapter III

Methodology

Design

"Phenomenology is a qualitative research method that explores and describes everyday experience as it appears to human consciousness in order to generate and enhance the understandings of what it means to be human" (Fain, 1999, p. 220). This method was selected with a goal of understanding the meaning of a lived experience of an individual with type 1 diabetes in relation to diabetic neuropathy.

Being a philosophy and a research method, phenomenology is a way of viewing and studying the world of everyday life. “Phenomenology, as a method, is a rigorous, systematic investigation of phenomena. The approach is a descriptive, retrospective, in-depth analysis of a conscious lived experience, which is everyday experiences that are real and true to the individual”; moreover, “the purpose of phenomenology is to describe the intrinsic traits or essences of the lived experience” (Fain, 1999, p. 221).

Participants

Participants included 3 juvenile children that had been diagnosed with type 1 diabetes for more than 1 year between the ages of 3-11 and their care-providers as well as 1 adult diagnosed later in life with type 1 diabetes. Volunteers where chosen from a local familial support group of the Helena area. Researcher had prior contact with the group through events and speaking which allowed her to publicly address the group discussing research and need for volunteers. No recruitment materials were used. The first four volunteers wanting to participate were chosen for research and contacted through email establishing a meeting time for the interviews. Names and associations were not released
to chosen participants.

Data Collection

This study is qualitative, based on phenomenological research that describes experiences as they are lived. "Nursing practice is guided by a holistic model that reflects the interrelationship of body, mind, spirit, and environment" (Fain, 2004, p. 220). The purpose of this research was to gain a deep understanding of the lived experience among children and their families with type 1 diabetes related to diabetic neuropathy. Within the framework of phenomenology the method followed Giorgi's Method requiring an interview/written description of 2-10 people who have lived with the experience under study (Fain, 2004). Data was gathered by interview. Participants were asked questions regarding how much they know about diabetic neuropathy, how this knowledge was acquired, and how this knowledge affected their diabetes management. See appendix B for interview template and informed consent.

Data Analysis

Data was analyzed using Giorgi's Method, which requires 2-10 persons who have lived the experience under study with the data generation through interview or written description:

(a) Read the entire disclosure of the lived experience straight through to obtain a sense of the whole.

(b) Reread the disclosure to discover the essences of the lived experience under study. Look for each time a transition in meaning occurs. Abstract these meaning units or themes.

(c) Examine meaning units for redundancies, clarifications, or elaboration. Relate
meaning units to each other and to a sense of the whole.

(d) Reflect on the meaning units, and extrapolate the essence of the experience for each participant. Transform each meaning unit into the language of science when relevant.

(e) Formulate a consistent description of the meaning structures of the lived experience for all participants (Fain, 2004, p. 230).

Rigor

The validity of this study was maintained through the evolvement of my thesis director who helped me identify my biases prior to the initiation of my data gathering. Furthermore, during the analysis of the gathered data and development of resultant themes my thesis director reviewed and critiqued my progress. Finally, at the conclusion of the research and incorporation of the data into the document the thesis draft was reviewed and compared to the original list of biases in order to identify any partiality or predisposition.

Bracketing

Bracketing is setting aside what the researcher knows about the phenomenon of the topic researched to prevent bias or influence of the study results. The research completed for this paper is a personal subject to me, the researcher. My older sister was diagnosed with type 1 diabetes in 1993 and I was diagnosed six months later. I have lived with this chronic disease for fifteen years and have felt, experienced, and struggled with many of the same issues presented by the families I interviewed.

Despite the closeness special interest I have in diabetic education and awareness I attempted to keep my biases and personal experience from influencing or guiding my
research. My motive is to present a study with concreteness and validity that provides
evidence about the lived experience of type 1 diabetes and how that affects the family.
Through the process of this research and from listening to the stories of life from the
participants of this study I learned more about my own care and myself.
Chapter IV

Results/Facts

This research was initiated to develop a deep understanding of the lived experience among children and their families with type 1 diabetes in relation to care and knowledge of diabetic neuropathy. The participants of the study described living with diabetes as affecting all aspects of life from activities, meal times, daily routines, and food provided in the home. Many of the families felt isolated and abandoned in maintaining care for their child with diabetes by care providers; furthermore, knowledge related to complications was reflective of fear rather than understanding and prevention. Four themes gleaned from the phenomenological research to be further discussed include keeping vigilance, challenging lifestyle, focusing care, and coping with diabetes. See appendix A for themes table.

Keeping Vigilance

The health care required for diabetes is pervasive. Maintenance of this chronic disease entails numerous blood sugar checks daily, diet and lifestyle routines, multiple medication dosages, with vigilance for any change in behavior signaling a change in blood sugar. A childhood diagnosis of diabetes often encompasses the entire family because successful management requires such intensive therapy.

Young children do not often recognize the important physical symptoms of both high and low blood sugars for what they are, or may not be able to verbally communicate what they are feeling delaying pertinent treatment. When questioned about how a mother recognized her daughter was experiencing a low blood sugar she commented, "She can tell but doesn't always relay it as having a low blood sugar, I think. Sometimes she
doesn't say anything and she just starts to be kind of irritating and you think, huh, and you check it and she's low."

Another concern of families with children diagnosed with type 1 diabetes is the potential for complications. A father within the study stated that his motivation for his personal diabetic care was the fear of complications. None of the families had received adequate education from their health care provider, and those that did already had some knowledge of diabetic neuropathy acquired by their own efforts. Doctor visits left the families frustrated and feeling more isolated that before. One family skipped their last appointment with the endocrinologist, "because we felt it wasn’t worth it, he doesn’t tell us anything." The primary mode of education concerning better control, new treatments, and prevention of complications was self-education and experience.

To understand the difficulties in treating and maintaining euglycemia and the importance of keeping vigilance one must understand the unpredictability of type 1 diabetes. Particularity during adolescence and the influx of hormones, especially growth hormone that can cause sudden uncontrollable and unpredictable periods of increased insulin demand and resistance. A mother with a thirteen years old son describes the frustration of this occurrence, "I mean, he could do everything the same every single time, and for some reason the numbers could be higher."

_Challenging Lifestyle_

In two of the families the fathers also had type 1 diabetes. When questioned about how this affected the dynamics of the family both stated an increase in tension and a propensity for conflict with a low blood sugar—"It was the lows that cause problems, when he would get really irritable with the world and we’d have a little spat." Another
difficulty for spouses with children diagnosed with diabetes is the inability to engage in
the school-age social development “where one mom will call another and say, “I’ll take
your kid this afternoon if you can take my kid tomorrow afternoon,” and they go off and
do something.” Another issue of concern was the redevelopment of a sense of normalcy
and eating in public, one family stated, “It [diabetes] makes you a little bit of a spectacle
to have diabetes, but it especially makes you a spectacle when two out of three members
of your family have diabetes.”

Another challenging aspect of life with a child diagnosed with diabetes is
maintaining blood sugar control and administration of insulin during school. Local
schools require the child to perform glucose checks and either insulin shots or pump
boluses in the school nurse office. However, this requires the child to leave the classroom
for longer periods interrupting valuable time in the class curriculum. This was more of an
issue with the younger children in elementary school and what the parents related as a
control issue with the school nurse.

Finding healthcare in the Helena area for pediatric care for type 1 diabetes is also
another issue for families. The first specialist a family saw after diagnosis came from out
of state and resulted in a very unpleasant experience. When the mother asked about a
local support group other than the 30 minutes they got every six months the physician
responded, “your out of luck.” Another child would get “physically sick to [his] stomach
because he’s so nervous of the high numbers” when it was time for a doctor appointment.
In acquiring new treatment options like the insulin pump for pediatrics it was the parents
that, “Pushed it. We became aware of it and then talked to other people, and then we
pushed for it hard to get approved.” When one of the fathers was diagnosed with diabetes
Type 1 Diabetes

while in the military he was told to take his insulin and never eat any sugar. It was not until his son was diagnosed years later that carbohydrate counting was explained.

_Focusing Care_

When asked about the first reaction to the diagnosis of diabetes, one father stated, "Oh, we were overwhelmed for a long time. Our first reaction was more fear." A common theme through all the interviews was the expression of fear for the uncontrollable and the complications of diabetes. Another mother stated, "plus it’s your child so it’s more scary." One diagnosis experience for a family was made more stressful because the health care staff assumed that because the father had diabetes that no further education was necessary.

The care that the families have received for their child’s type 1 diabetes was "pretty much geared toward day-to-day stuff and the specific questions that [the parents] have, which are usually related to daily maintenance and the best way to do things." One family stated, "I feel like we’re diabetic educators, you know. So I don’t think they know any more than we do." In all participants, care is very self-directed and controlled. The father of one family stated, "I guess we try to recognize patterns, and if it stays high for a week or something, then we’ll either change the carb ratio [...] or the basal ratio."

_Coping with Diabetes_

To coping with the overwhelming and life-changing diagnosis of a child with diabetes all of the families pointed out hidden benefits for having diabetes including the requirement of a healthy diet, an increased involvement in their child’s life, and a motivation to exercise to promote health for their child. One mother stated, "There are
pros with it too. I mean, we’re more involved with her, we see her more than we probably would.”

Another couple focused on food to bring the family together because, “Food is fun to talk about, and I think we probably eat healthier than if nobody had diabetes in our family.” However, the difference between siblings with a diagnosis of diabetes can also affect how a family copes. When asked specifically how one family balanced the extra attention a child receives with diabetes the mother commented, “I know initially it was a real source of jealousy. She felt that he got a lot more attention than her. I remember at one point her just walking up to me and saying, “If I hear diabetes one more time, I’m going to scream”.”

Several families were also concerned about how their children would become involved in their own care and if the children would develop a healthy sense of independence with the parents, being so involved and watchful. During one interview, when questioned about how involved or interested their four year-old daughter was in her care they responded, “When she first masters a new skill she’s more interested in doing it than after a while. But she understands a lot.” Although concerned about their daughter’s coping ability and perhaps lack of autonomy, they encourage her to participate in her care but do not force her involvement.
Chapter V

Discussion

Keeping Vigilance

The demands a diagnosis of type 1 diabetes places on the responsibility of a parent exceed normal expectation. Several of the families have an established routine of multiple blood glucose checks through the night waking every two to four hours, still maintaining a full-time job, and raising a family while attempting to create a normal family environment. A child with type 1 diabetes is totally dependent upon the parents to provide the needed medication, vigilance, and education, as well as the support, stability, and continual love. While fulfilling the necessary role of the “treatment enforcer” the parent is placed in an advocacy role instead of providing sympathy during injections, blood glucose checks, and diet restrictions. Parents are apt to suffer from caregiver role strain because of the pervasive, intensive, and vigilant treatment that diabetes requires to prevent both short and long term complications.

Challenging Lifestyle

Diabetes requires that adaptations be made to life. No longer is dinner at Pizza Hut an option for dinner for one family because of how it affects the daughter’s blood sugar, so the mother now has created a recipe with reduced carbohydrates so they can still eat pizza. For another family, to go swimming had to be a planned occasion with alterations to the insulin pump site the evening before to ensure site integrity. The first day of school is a right of passage toward discrimination and a realization of perceived inferiority. Although the Individuals with Disabilities Education Act of 1991 prohibits discrimination against children with disabilities and requires that accommodations should be made within a child’s school setting with as little disruption as possible and allowing
as full as participation as possible, this continues to surface as a point of tension for most families. The American Diabetes Association states that, “Both the parents and the health care team should work together to provide [...] the information necessary” (2008). However, in two of the families, it was the parents who were expected to fulfill all educational obligations to the school nurse and the teachers; and regardless of their efforts the child was still forced to leave the classroom multiple times in order to perform a blood glucose check. A parent with a child diagnosed with type 1 diabetes is forced to be an advocate for the child to ensure basic rights and opportunities.

**Focusing Care**

The lack of education and support given to parents with children diagnosed with type 1 diabetes is deploring. Many were forced by necessity to create their own methods of care as well as complete excessive self-education about the disease and appropriate standards of care for their children. Trial and error is used predominately to self adjust medication dosages and treat hypoglycemic events. Unfortunately, the parents with child with diabetes often know more than their care practitioner. In the treatment of diabetes for many families, it has been the parents who researched, promoted, and initiated current treatment options like insulin pumps, Lantus insulin, and other adjunctive therapies. In trying to acquire adequate care, families of the area have found it difficult to find a physician who is qualified to take pediatric patients with type 1 diabetes and clinics 2 to 4 hours away do not readily take new patients. Furthermore, the education that families do receive is usually about only day-to-day treatments; ignoring the important discussions about potential complications like neuropathy, follow through of important yearly eye and dental exams, and sick-day management during an illness. One family had to take
their child to the emergency room for diabetic ketoacidosis when sick with the noro-virus because they did not know to continue giving insulin although the child was not eating.

*Coping with Diabetes*

The diagnosis of a child with diabetes is an overwhelming experience for a family. Most do not even fully understand the disease or how it will affect the entire family unit. Tension can develop between the parents as well as sibling jealousy because of a sudden decrease of attention. Children often become perceptive of their neediness and are propelled toward maturity and self-reliance because of their diabetes, but this can lead to isolation and a sense of loneliness. To be different from one’s peers and then receive special attention from adults adds continual stress to a child that just wants to be a kid. According to Bonner, Hardy, Guill, McLaughlin, Schweitzer, and Carter (2005), consideration of the family unit is critical because of the impact of parent/child functioning upon effective treatment.

Furthermore, “studies of chronic illness samples over the past 25 years have consistently identified family functioning as an important predictor of psychological functioning of children with chronic illness” (find source). An assessment of available emotional resources is also important to the parental adjustment to chronic illness. Parents in several families expressed a sense of sorrow and long-term uncertainly related to the unpredictability of the disease. The mothers especially expressed a desire to ease the suffering of their children, desiring if possible to take the disease on themselves. The management of diabetes is a common source of conflict between parents and the child that also affects coping with the chronic disease. Negative emotions often surround blood glucose monitoring, quality of life, and the perceived burdens of diabetes; however,
families attempt to present a controlled and positive outlook to questions and concerns resulting in isolation and guilt. When questioned what his blood glucose level is one child responded that he always said 120 despite what was the actual reading. A high glucose is commonly responded to as a “bad” reading and the child is considered at fault resulting in guilt and fear of punishment.

Additionally, when certain foods are strictly prohibited a child is at risk to develop an unhealthy relationship with food. For example, consuming large quantities of high sugar/carbohydrate foods when unobserved and unable to use discretion and moderation when eating. Adolescent girls with diabetes are at an increased risk of using diabetes and the fat eliminating process of diabetic ketoacidosis to lose weight. It is vitally important to perform a through assessment and evaluation of the family and child’s coping and adjustment to life with diabetes at every routine visit.

**Future Research**

Although research has increased concerning the family conflict and behavioral adjustments that occur with the development of type 1 diabetes, education has not been increased or readily available to families. Parents need to be provided with diverse learning opportunities and resources as well as support and community contacts that could assist with the adaptation to life with diabetes. Continued assistance and availability of adequately prepared care providers is vital to the successful management and treatment of a child with diabetes as well as the development of local community support groups.

Research is needed to develop evidence-based practice standards for education about type 1 diabetes for children, parents, and practitioners. Prevention of acute
hypoglycemic events as well as long-term complications is another important topic that needs promotion. None of the families interviewed understood fully why good glucose control was important or all the effects high glycemic levels had on the body.

Furthermore, the new technological treatments and advances in diabetic care need to be made more available to patients with diabetes. The current pharmaceutical system restricts tools that facilitate adequate glycemic control because of patient’s financial inability to afford prescriptions and the refusal of insurance policies to cover certain medications. Families with children diagnosed with diabetes need health care advocates to have the ability to acquire sufficient education, support, and prescriptions.
Appendix A: Themes chart
Appendix B

Informed Consent Form

Carroll College
Subject Consent Form
For Participation in Human Research

Project Title: Type I Diabetes Mellitus: Diabetic Neuropathy

You are being asked to participate in a research study concerning the amount of education provided about diabetic neuropathy among individuals with Type 1 Diabetes. This project may help nurses better understand the perceptions and understanding of children and parents regarding their understanding of diabetes, and if they are receiving education about contributing factors and common symptoms related to the diagnosis of diabetic neuropathy as well as the effective treatments including medications and other therapies. You must have a diagnosis of Type 1 Diabetes for greater than 1 year. If you agree to participate in this study, general information will be gathered at an interview including the following: age, time of diabetic condition, how you were diagnosed, family history, other illnesses, gender, and education. Information gathered will be kept confidential by participant code numbers—eliminating use of names. This voluntary study will have no known risks or benefits to you; however, there may be discomfort associated with discussing potential diabetic complications and current diabetic management.

Photographs may by used for publication and presentation.

Standard authorization statement:
AUTHORIZATION: I, ______________________ (name of subject), agree to participate in this research. Joni Franchini has thoroughly explained the nature and process of this research to me and I am aware that I can contact her with questions at (406) 447-4899. I understand that I have the right to refuse to participate in this study and that refusal to participate will involve no penalty. I have received a copy of this consent form for my own records.

__________________________________________ Date
Signature of Participant

__________________________________________
Printed Name of Participant

__________________________________________ Date
Signature of Witness

__________________________________________
Printed Name of Witness
Project Title: Type I Diabetes Mellitus: Diabetic Neuropathy

You are being asked to participate in a research study concerning the amount of education provided about diabetic neuropathy among individuals with Type 1 Diabetes. This project may help nurses better understand the perceptions and understanding of children and parents regarding their understanding of diabetes, and if they are receiving education about contributing factors and common symptoms related to the diagnosis of diabetic neuropathy as well as the effective treatments including medications and other therapies. You must have a diagnosis of Type 1 Diabetes for greater than 1 year. If you agree to participate in this study, general information will be gathered at an interview including the following: age, time of diabetic condition, how you were diagnosed, family history, other illnesses, gender, and education. Information gathered will be kept confidential by participant code numbers—eliminating use of names. This voluntary study will have no known risks or benefits to you; however, there may be discomfort associated with discussing potential diabetic complications and current diabetic management.

Photographs may be used for publications and presentation.

For the participation of a minor (under 18 years of age) or other person not able to give consent for himself/herself:
AUTHORIZATION: I ____________________________________________ (name of parent or guardian), related to the subject as ____________________________________________ (relationship), agree to the participation of ____________________________________________ (name of subject) in this research. Joni Franchini has thoroughly explained the nature and process of this research to me and I am aware that I can contact her with questions at (406) 447-4899. I understand that the subject or I may later refuse participation in this research and that the subject, through his/her own action or mine, may withdraw from the research at any time without penalty. I received a copy of this consent form for my own records.

__________________________________________________________
Signature of Participant’s Parent or Guardian

_________________________ Date

_________________________ Printed Name of Participant’s Parent or Guardian

__________________________________________________________
Signature of Witness

_________________________ Date

_________________________ Printed Name of Witness
Appendix B Continued

Interview Template

Age_______ Gender_______ Race_________ Current Address: Town/County

Number of years with diabetes: ____________

How were you Diagnosed?

Do you have a family history of Type I diabetes?

Do you have any Nondiabetes conditions?

Do you have any diabetic complications?

Do you have any other medical diagnosis?

Has a healthcare provider ever told you that you have diabetic neuropathy?

Have you ever received education from a medical provider concerning diabetic neuropathy?

If so, how has this education affected your personal diabetic management?

How has this education affected your personal diabetic management?

Is there anything that you would like to share with me about your diabetes that I didn’t ask?
References


Wilson, D. J. (2005). Amputation and the diabetic foot: Learning from a case study. *British Journal of Community Nursing, 10*(12), Wound Care: s18, s20, s22.